

Appendix S1 – Reflexivity statement

1. How does this study address local research and policy priorities?

The study was conceptualized by international and national civil society and community representatives of people living with and affected by HIV, working in collaboration with a social scientist in a high-income country (SLMD). The study aims to gather empirical realities on the digital transformation of health to inform policy recommendations. This is an issue of emerging concern for diverse young adults in low- and middle-income countries (LMICs), as well as for global health finance and governance agencies.

2. How were local researchers involved in study design?

As the process took place during the Covid-19 pandemic in 2020-21, we met through a regular schedule of videoconference calls to develop and conduct the study. We formed a global consortium including a steering committee with civil society managers and social scientists (including the Global Network of People Living with HIV, GNP+), and a research team including early career researchers from each country, supervised by the principal investigator.

In Kenya, the national partner was the Kenya Ethical and Legal Issues Network in HIV & AIDS (KELIN). In Ghana and Vietnam the national partners were the executive directors of the Ghana National Association of People Living with HIV (NAP+ Ghana) and the Vietnam Network of People Living with HIV (VNP+). Their participation in the study was facilitated and supported by GNP+. Each national organization applied for ethical approval in their own country, and identified a national researcher (TP, IK, AM and TI) to conduct the research with ongoing training and mentorship (from SLMD, TO and NM).

Thus both senior managers and local/junior researchers participated in study design from the outset through monthly and weekly videoconference calls, which are chaired by a different consortium member each time. The agenda for these meetings and all minutes are kept on a shared drive to which all consortium members have access.

Local researchers led workshops in each country to review and fine-tune the study instruments. Local researchers also recruited key informants and focus group discussion participants, drawing on their existing institutional networks. They were trained and mentored to conduct the interviews and focus group discussions, and exchanged advice with one another through the weekly consortium videoconference calls and through in-person field study exchanges in Ghana and Kenya.

3. How has funding been used to support the local research team?

All of the organizations in the consortium were joint applicants for a two-year grant from Fondation Botnar, and collaboratively co-authored the proposal and budget. The grant covered partial staff time for local researchers, senior managers and social scientists at the Geneva Graduate Institute. The Graduate Institute was the main grant recipient, coordinating timelines and reporting to the donor on behalf of the consortium.

4. How are research staff who conducted data collection acknowledged?

They are listed as co-authors. Some junior collaborators who participated more sporadically are acknowledged in the acknowledgements section.

5. Do all members of the research partnership have access to study data?

Yes. The consortium has signed a data management policy which clarifies that the data from each country is the property of the national organization. Data from any of the countries may be used by other consortium partners for publication, with written approval of the national organization. In Kenya, in compliance with the requirements of the ethical approval, data may only be shared with a signed data protection agreement.

6. How was data used to develop analytical skills within the partnership?

The data was used to develop analytical skills during the research process as follows: a) Researchers drafted inception papers based on desk review of laws and policies collaboratively; b) STOPAIDS led the consortium in an online workshop to develop a joint advocacy strategy, and to develop shared talking points for external speaking by all consortium members; c) Over the course of the two-year study, the consortium held regular informal discussions of emerging news relating to digital health and human rights, and held monthly strategic calls with guest lecturers on topics related to the study topic, discussing emerging observations collectively in reference to these presentations; d) Researchers traveled between countries to participate and support each other during the data-gathering and to discuss initial observations; and e) Consortium members co-organized webinars and conference panels at which we presented our analyses to colleagues and the public, and we discussed these as a consortium before and afterwards.

In this way, while data-gathering was underway, the consortium gradually developed a shared analysis of the benefits and risks of the digital transformation in health. This provided a foundation for our collective interpretation, described below.

7. How have research partners collaborated in interpreting study data?

The research team in each country held debrief sessions after each FGD and KII and discussed collective observations as the study was underway, capturing these in written reports to accompany the transcripts. SLDM, TS, KL and AM presented the draft codebook to the consortium for revision and input. They also conducted initial qualitative analysis of data and presented draft findings to the consortium on the monthly strategic calls for input. The local researchers presented the draft findings and policy recommendations to study participants in national virtual workshops for discussion and input.

SLMD presented a final analysis to the full consortium at an in-person workshop convened by KELIN in Nairobi. The local researchers then presented feedback from the validation workshops. The findings were reviewed, discussed and revised by the consortium. Local researchers led the presentation of findings and policy recommendations to the project advisory committee.

8. How were research partners supported to develop writing skills?

Local researchers (NM, NW, TI, IK and TP) collaborated to draft two inception papers based on the initial desk review of laws and policies, with mentoring and feedback from senior

managers and SLMD. SLMD and other senior managers in the consortium have also identified opportunities for young researchers to write about the study and have mentored them to write a book chapter, blogs and a chapter of an NGO report based on the study findings.

As most of the research partners have not experienced writing for a peer-reviewed publication before, the process of co-authoring a previous commentary for BMJ Global Health, as well as co-authoring this article, have also provided opportunities for some research partners from civil society to learn about the peer-review process.

9. How will research products be shared to address local needs?

The research has been used by GNP+, KELIN and STOPAIDS staff to collaboratively develop a policy brief in user-friendly language, and to translate it into Spanish. The policy brief and research was presented in two online webinars with experts from the research consortium and from UNDP and WHO, with consortium partners recruiting hundreds of participants from the study countries to participate. STOPAIDS, GNP+ and KELIN also convened online discussions through the RightsCon conference to share the research findings, as well as in online youth workshops and in briefings for young people living with HIV. National organizations in the consortium have also presented the research findings within their own countries, and have been invited to speak to international organizations, UN agencies and national governments about the research findings.

In addition, GNP+, KELIN and STOPAIDS are also collaborating to support the mandate of the UN Special Rapporteur on the Right to Health, Dr. Tlaleng Mofokeng, to hold consultations, develop submissions, and publish her report to the UN Human Rights Council on digital technologies, innovation and the right to health. They will then use the report to hold national and regional dissemination meetings with other civil society partners.

10. How is the leadership, contribution and ownership of this work by LMIC researchers recognised within the authorship?

The researchers who participated in the study are all listed as co-authors. We acknowledge, however, that the first author is based in a high-income country. The primary reason for this is that she led the project and drafted the article.

11. How have early career researchers across the partnership been included within the authorship team?

The majority of co-authors are early career researchers (TP, TO, IK, NM, AM, KL).

12. How has gender balance been addressed within the authorship?

Three authors are male (AM, TS, TW, CN) and eight authors are female (SD, TP, IK, TI, NM, EA, NW and KL). We feel that given the under-representation of women in digital design and governance, it is an important contribution that we have a majority of women from LMICs listed as co-authors.

13. How has the project contributed to training of LMIC researchers?

The authorship team is primarily composed of early career researchers from LMICs. For most of the co-authors, this is the first peer-reviewed publication, and their first experience participating in a social science study, and thus the project has significantly enhanced their skills and experience in research and analysis.

14. How has the project contributed to improvements in local infrastructure?

This project has not directly contributed to improvements in local infrastructure.

15. What safeguarding procedures were used to protect local study participants and researchers?

We have consulted closely with local researchers and civil society groups to identify and address any security risks proactively.