Maximising the positive potential of digital communications in HIV and sexual health responses

A summary of Avert's webinar held on 22 July 2021

Introduction

Digital communication presents new opportunities to achieve good health literacy. It offers the scope for tailored, targeted and engaging content; and to involve end-users in the design and implementation. However, the *potential* of digital health communication is not always reflected in its *actual* use. We need to work together to ensure that digital communication achieves its potential impact on global HIV targets. The urgency is clear, given the recent UNAIDS report highlighting our collective failure to meet the 2020 global prevention targets.

Four panellists provided insightful presentations:

- Pradeep Kakkattil, Director of the Office of Innovation at the Joint United Nations Programme on HIV/AIDS (UNAIDS), Switzerland
- Alexander Medik, Business Innovation and Partnerships Lead, Aidsfonds, the Netherlands
- Takunda Chanetsa, U Report and Boost Coordinator, Africaid-Zvandiri, Zimbabwe
- Irene Kpodo, Project Officer, National Association of People Living with HIV (NAP+), Ghana.

The discussion covered four key themes:

- Health literacy
- Partnerships, collaboration and co-creation
- Innovation and ethics
- Sustainability and scale

Health literacy

Health information is a right, and a foundation to achieving good health. Avert's Chief Executive Officer, Sarah Hand, highlighted how information on HIV and sexual health enables people to understand and assess risk, gives them agency and supports informed decision-making and self-care. Takunda Chanetsa emphasised the right of every child to access information, citing his experience at Zvandiri where he has witnessed adolescents' lack of understanding of HIV treatment resulting in poor decision making and corresponding problems with ART adherence. Alexander Medik addressed the need to provide evidence-based, sex-positive comprehensive sexuality education to young people. This should be available both on and offline, be designed to meet young people's needs, and counteract the predominantly negative focus on disease prevention. A focus on pleasure, including issues of consent, safety, privacy, communication and self-determination, helps young people to negotiate sexual relations. There is growing evidence that people with more positive views of sexuality are more likely to be assertive, practice safer sex, use contraception consistently, and have higher sexual self-esteem.

Good health communication programmes build **health literacy**. When we are literate, we are knowledgeable and empowered to make informed choices that have positive impact across the HIV prevention, treatment and care cascade.

Partnerships, collaboration and co-creation

The Covid-19 pandemic shone a spotlight on the role of digital communication in promoting health literacy, while also drawing attention to the challenges of a corresponding 'infodemic' and the need to navigate 'fake news'. The discussion made reference to the Principles for Digital Development. Information provided online should be high quality and from trusted sources. Pradeep Kakkattil urged us to reflect on the lessons from the early AIDS movement, and make sure that those with lived experiences are included in the (digital) space – asking us to imagine the power of the collective voice of the 26 million people with HIV around the world. Online platforms such as VOICE+, coordinated by the Global Network of People Living with HIV (GNP+), aim to bring together and 'collectivise' the voices of people with HIV.

Takunda expanded on the importance of ensuring that messages are trustworthy and generated by communities. He described his own experience co-creating Avert's Boost app, developed to support community health workers and peer educators with the information they need, and his role coordinating U-Report, a free, anonymised SMS platform that allows young people to access information about HIV prevention, care, treatment and support. He advised that it is important to identify the target group and involve them in planning and design processes to ensure that information is tailored, age-appropriate and available in local languages. Communication should be delivered through digital platforms that are widely accessible on mobile devices.

Innovation and ethics

The transformative potential of digital innovation needs to be balanced with a focus on ethics, acknowledging the importance of taking a rights-based approach to digital health communication. Pradeep cautioned us to use existing technologies and 'go where people are', rather than creating new tools and platforms. Digital technologies have the potential to build upon and support 'in person' consultations to deliver health information, and there was a call to donors and partners to invest more in digital approaches.

Takunda raised the need to increase the security of digital applications to respect and maintain the privacy of information, with Irene Kpodo expanding upon this issue. Representing the Digital Rights Advisory Group (DRAG), she discussed mitigating the potential negative impacts of digital interventions in health on human rights, especially the rights of young people and the most marginalised.

Irene raised the issue of confidentiality of HIV and SRHR information for stigmatised or marginalised groups, such as people with HIV or people who are LGBTQI+, particularly as they may also be criminalised. In these contexts, individuals may feel uncomfortable sharing their status or being open about their sexual orientation via digital means. We must address the ethics around digital communication and data security and safety when information is gathered and stored; and increase digital literacy. Some countries do have laws and policies in place; for example, the Ghana Data Protection Act and Data Protection Commission; and we need to make sure that people have information and are empowered to make use of the laws that protect them.

Sustainability and scale

Alexander Medik raised concerns that donors and implementers develop digital health solutions in silos, leading to fragmented approaches and young people being bombarded with information from different, uncoordinated and individually branded digital products. Large numbers of short-term pilot projects have led to a lack of scale and sustainability of digital communication. He called for better coordination of our digital efforts for greater impact. Aidsfonds has aimed to address these issues through its Stepped Care Model. Pradeep also referred to the issue of 'pilotitis', urging donors to avoid duplication, which results in a fractured space and the lack of a common digital framework.

Alexander noted that most countries lack adequate digital health policy and infrastructure. Policies, regulations and governance models have not been adapted to meet the needs of digital communication. To realise their potential, digital health initiatives need to be guided by an integrated digital health strategy to ensure coordination amongst different stakeholders and ideally led by government. At a global level, coalitions such as The Digital Connected Care Coalition and Transform Health aim to tackle these systemic challenges, to achieve universal health coverage through the digital transformation of healthcare and support, and use of digital technologies and data.

Conclusion and recommendations

Avert's mission is to increase health literacy on HIV and sexual health among those most affected in areas of greatest need, in order to reduce new infections and improve health and well-being. This is outlined fully in our new strategy. We welcomed this opportunity to bring together those interested in digital health communication to share reflections and look forward to working in partnership with donors and implementers to realise the potential that digital communication offers to make a positive impact on HIV and SRHR outcomes. As Pradeep said so vividly, we invite you to join with us to walk the digital streets!

Summary of key recommendations

- Address the structural factors that restrict access and perpetuate a 'digital divide', such as reducing or eliminating the cost to access the internet. The recent IAS Policy Brief on digital technologies reported that Africa has the world's most expensive data, representing 8% of average income in African countries.
- Use existing technology and digital spaces that are widely accessible and used, including providing digital content off-line to address inequalities experienced as a result of the 'digital divide'.
- Involve young people and communities in co-creating digital content to ensure that information is trustworthy, targeted and appropriate to their needs.
- Provide online content that is sex positive and addresses safe, consensual and pleasurable sex.
- Take a rights-based approach to digital health communication that addresses the privacy and security of information.
- Strengthen digital literacy to ensure that everyone is aware of, and empowered to make use of existing data protection laws designed to maintain their privacy, confidentiality and security.
- Strengthen the coordination of digital efforts to achieve scale and sustainability of digital health communication, avoiding duplication and fragmented approaches caused by short-term pilot projects.
- Support the development of more integrated digital health strategies that promote coordination of digital health initiatives amongst different stakeholders, ideally led by government.

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