

## A. SUMMARY OF DISCUSSIONS, CONCLUSIONS AND RECOMMENDATIONS<sup>1</sup>

In 2022 the Reference Group met three times, twice online and once face-to-face. Speaking as an independent voice, the Reference Group issued a public statement on Pandemic Preparedness and Response and published an article on Decriminalisation in the journal Sexual and Reproductive Health Matters.

A summary of the discussions and conclusions of the Reference Group at its various meetings in 2022 are set out below.

### Reference Group priorities for 2022

In June 2022 at an online meeting, the Reference Group adopted a set of priorities based on its Terms of Reference:

- Decriminalisation linked to the 10-10-10 targets
- Pandemic preparedness, human rights and the impact on people living with HIV (and key populations)
- UNAIDS Re-alignment processes
- Digital technology in the context of HIV and human rights
- Humanitarian responses in situations of conflict

### Reference Group Statements in the period:

- Statement: [Rights, Readiness and Response: Written comments on the working draft of the WHO convention, agreement or other international instrument on pandemic prevention, preparedness, response and recovery 15 September 2022](#)
- [Decriminalisation and the end of AIDS: Keep the promise, follow the science and fulfil human rights](#)

### A.1. Summary Outcomes of the 23<sup>rd</sup> Meeting of the Reference Meeting held on 7th June 2022

The Reference Group met to identify priorities for the year. It then held a broader meeting on digital technologies and the right to health, inviting UN Joint Programme on HIV/AIDS cosponsors to participate in the discussion.

### Reference Group priority areas of concern:

The following issues were identified as areas of concern to the Reference Group:

- The need for further conversations with key funders on the redirection and refocusing of resources to regional advocacy work that's based on the human rights of key populations, This is essential given the current lack of support for **regional advocacy** on the rights of key and vulnerable populations.

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<sup>1</sup> This report was prepared by the Secretariat of the UNAIDS Reference Group on HIV and Human Rights. The views contained herein are those of the members of the Reference Group and do not necessarily reflect the views of the UNAIDS Secretariat or the Co-sponsors of the Joint Programme.

- The need to improve civil society representation in discussions on Pandemic Preparedness and Response.
- The **criminalisation** - of sex work, same-sex relationships, drug use and simple drug possession, and HIV criminalization - particularly in the lead-up to the 2019 ministerial statement mid-term review in 2023.
- **Access to medicines**, diagnostics and therapeutics as a human rights issue.
- The **outcomes of the UNAIDS Re-alignment process**, as well as the capacity of the Joint Programme to achieve its goals (following up on the [statement](#) from 2021).
- **Digital technology** in the context of HIV and human rights.
- **Humanitarian responses** in situations of conflict considering geo-political tensions across the world, particularly relating to the rights of migrants and other vulnerable populations in the context of the HIV response.

### **Outcomes of the Digital Technologies, HIV and Human Rights Consultation**

This discussion began with a presentation from UNDP and was chaired by the Reference Group Co-chairs.

The presentation outlined the various barriers and rights violations that may occur in relation to the use of digital technologies, while at the same time noting the positive opportunities that digital technologies provide, especially for key populations and structurally excluded people. UNDP noted the importance of placing an emphasis on ensuring programmatic frameworks identify potential rights violations and inequalities and outline actions to address barriers to safe access, using a focus on the framework of the right to health.

The digital divide is an important consideration in the conversation on digital technologies. Moreover, in developing countries, data protection and the risk that users' data will be accessed by governments or other conducting surveillance is a significant issue. The Reference Group noted the misuse of data and lack of data protections as an important issue to address.

The gender digital divide and generational digital divide were also discussed as an issue. Young people at community level including those leading in the response to crisis and emergencies and other contexts, are often leaders in the use of digital technologies. Youth leadership is something that the Reference Group should look at, since there are innovations there, with limited recourses, to counteract the human rights backlash.

Considerations of the needs and vulnerabilities of criminalised populations are largely absent from conversations on digital technologies (particularly outside of health/HIV sectors). Criminalised populations must be included in discussions around the use of digital technology for health, to ensure that any use of digital technology for health does not exclude criminalised groups and allows them to access online services safely and securely.

There are additional concerns in relation to data protection. While many countries have adopted data protection laws, the challenge is often in their ability to enforce these. Where we are advocating for data protection laws, we must also emphasise their implementation and enforcement.

The Reference Group heard from a number of UN agencies regarding their work on digital technologies, health and protecting rights. UNICEF reported that it has a broad range of experience with implementing digital technologies for health, especially for families and young people. UNICEF's [U-Report messaging system](#) is one of the largest global platforms that brings together young people from many parts of the world into a forum where they can express themselves on a broad range of

issues including health, governance and civil rights. UNICEF is working with a partner called [D-Tree](#) who are leading in a landscape analysis of digital tools for HIV prevention among Key Populations.

The Reference Group heard from participants on concerns regarding digital technologies and their application in interventions targeting people in prison settings. People in prison settings have limited access to health care services and legal advisors and are deprived of liberty – a question remains as to the implementation modality and concerns about confidentiality when using digital technologies in prison settings. During COVID, in many countries, including India, people in judicial custody who were required to appear in court, did so using digital technologies. This demonstrates the potential application of digital technologies for people in prison settings or detained. Many countries that lack infrastructure and staffing to deliver health care in prison settings would benefit from the application of digital technology. However, in many countries human rights are not a consideration, and the reality is that there is no concern for upholding principles of human rights to ensure data privacy or the health of people in prison.

A barrier for delivery of health care using digital technology is, for instance, that donors do not allow civil society organisations to access the dark web – which is where many of our clients are, especially people who use drugs. A principled approach to address this issue should inform our work and how we should work in such settings to deliver the information necessary for public health purposes.

The following conclusions emerged from the discussion:

1. That while digital technologies provide promising opportunities in terms of access to health services and information, barriers to access continue to feed inequalities. This includes a digital divide in terms of access along the lines of gender, age, socio-economic status and between countries in terms of infrastructure development. Accessing online information can be dangerous for people from criminalised and stigmatised groups, particularly where data security is an issue.
2. In terms of data protection, this continues to be an issue, particularly in the enforcement of data protection laws and issues of the misuse of data.
3. A human rights based approach is necessary when looking at digital tech for health, and programme developers and donors must make sure potential rights violations are identified and mitigated in all digital health projects. Young people who are using digital tech to uphold rights, particularly the right to health are key allies and partners in this work.

## **A.2 Summary outcomes of the 24<sup>th</sup> Meeting held on 1 and 2 November 2022, in Geneva**

The second meeting of the Reference Group took place on 1 & 2 November 2022, in Geneva. This was the first time the Reference Group had met face-to-face in over 2 years. The Reference Group met with various staff at UNAIDS and UNDP to discuss the human rights aspects of work relating to adolescent girls and young women, and on pandemic preparedness and response. During the two days, the Reference Group also organised a broader consultation on the role of the UN in supporting decriminalisation efforts globally and in countries. Below is a summary of the outcomes of each discussion.

### **2.1 Outcomes of the Meeting with UNAIDS Executive Director and Deputy Executive Directors**

The Reference Group welcomed the opportunity to meet with the Executive Director Winnie Byanyima and the two incoming Deputy Executive Directors, Christine Stegling and Angeli Achrekar. The Reference Group expressed appreciation for the Executive Director's leadership and support for Key Populations and the de-stigmatisation of drug use. We noted UNAIDS' continued commitment

to implementing the UNAIDS Strategy in the face of constrained resources and underscored the importance of UNAIDS' defending, reasserting and furthering the human rights of key populations.

- UNAIDS has been great at standing up for the rights of key populations and needs to continue this, advancing the human rights of key populations. We ask that UNAIDS and co-sponsors affirm this position on the rights of key populations and on decriminalisation and that this programmatic area of work is communicated and affirmed at the regional and country level, with clear guidance to UNAIDS Country Directors and teams as well as Regional Directors.
- The Reference Group particularly noted the needs of trans persons and recommended that the Joint Programme entrench the inclusion of gender-diverse people in programming – especially for trans women in SRHR work, and in preventing gender-based violence – when we speak of women, we must refer to women in all their diversity.
- The Reference Group took note of the Executive Director's concern on digital technologies and normative frameworks for the application of digital technology that is human rights informed, as this has been a concern of the Reference Group too. The Reference Group remains committed to supporting the development of such norms and standards.
- The Reference Group welcomes the work of UNAIDS on inequalities and recommends a greater focus on disaggregated data on basis of race, migration status etc.
- The Reference group notes that funding for communities on the frontline of the response is more critical than ever and that mechanisms for funding streams to these community-led groups must be strengthened.

Going forward, the Reference Group and UNAIDS Executive Director committed to having an annual face-to-face meeting and a second meeting online in the first half of the year.

## **2.2 Recommendations of the Reference Group:**

### **Decriminalisation**

The Reference Group hosted a broader consultation on the role of UN agencies in supporting criminal law reform to meet the Global AIDS Strategy law reform targets and Political Declaration on HIV 2021 commitments. The consultation brought in Joint Programme cosponsors, donors, key population-led organisations and organisations led by people living with HIV, including women living with HIV. The consultation asked participants to reflect upon what is being done that is working and needs to be scaled up, and to identify gaps, and possible new approaches to be considered.

Participants noted that leadership from UNAIDS on progressive and forward-looking support for decriminalisation of HIV transmission, and of key populations is welcome.

The Reference Group recommends strengthened leadership from UNAIDS at the regional and country level on decriminalisation, and engagement with regional leaders. This is especially relevant for the decriminalisation of sex work, where a more vocal and cohesive call for the full decriminalisation of sex work is critical.

- As the space held by civil society to engage in advocacy for decriminalisation has shrunk globally, the UN Joint Programme can create alternative spaces where civil society can engage with states at country and regional level.
- Given the paucity of funding for law reform activity, the UN has a role to play to advocate for support for community-led efforts for decriminalisation and community-led stigma

reduction, including with key funders such as the Global Fund and PEPFAR. This is more important than ever in resource-constrained environments.

- Given the important role that faith leaders and communities play in terms of law reform, particularly in relation to key populations, we recommend deepening engagement with faith communities, particularly faith communities that are supportive of and work with key populations, in the work of the UNAIDS and the Joint Programme.
- With regard to drug decriminalisation, we note that UNAIDS has a role to play in advocating for, and providing technical support for, a human rights-based approach to drug policy, including using the treaty bodies and other human rights mechanisms. There is a need to look beyond the current ‘good’ practice on drug policy to what practices would look like if they were consistent with international human rights law and public health standards.

### **Strengthening Human Rights in Programmes for Adolescent Girls and Young Women’s SRHR & Eliminating Structural Barriers**

The Reference Group heard from UNAIDS and cosponsors on the various programmes that are being undertaken in relation to the rights of adolescent girls and young women and sexual and reproductive health, including the Global Alliance to End AIDS in Children, Education Plus, and work on age of consent to access to services.

In terms of the Global Alliance,

- The Reference Group would like to engage in an ongoing conversation on how Key Populations are involved and consulted.
- We suggested that the working group for area 4, on societal enablers, be integrated into the other pillars, ensuring that all the pillars for the Global Alliance have a focus on human rights.

Members of the Reference Group were invited to join the working groups for the Alliance and the think tank of Education Plus. The Reference Group will consider this.

On Age of Access to Services,

- the Reference Group recommends that UNAIDS support countries in addressing age of consent laws. The Reference Group would be happy to provide inputs and advice in relation to these guidelines.

### **Pandemic preparedness and response**

The Reference Group met with the UNAIDS team working on Pandemic Preparedness, as well as a member of STOPAIDS, representing the Civil Society Consortium on Human Rights in Pandemics. The Group discussed the current negotiations on the Pandemic Preparedness Instrument. We emphasized the need to ensure access to medicines and strong language to support such access. We also expressed concern at the lack of access to the negotiations for civil society groups.

- The reference group agreed to remain cognizant of the progress of the International Negotiating Body negotiations and to consider converting the pandemic preparedness paper into a journal article.

### **2.3 Reference Group commitments:**

Throughout the discussions the Reference Group committed to certain actions to support the human rights work of the Joint Programme and the AIDS response more broadly, including:

- Contributing, where we can, to raise the alarm that resourcing UNAIDS and the response more broadly is critical.

- Being the vanguard of human rights in the context of HIV, and to being bold in furthering the rights of key and marginalised people and the leadership of communities.
- Affirm our support for the full decriminalisation of sex work and for progressive and forward-looking legal reforms on drug use and possession for personal use, and in addressing inequalities in access to medicines as a human right.
- Drafting and issuing statements on decriminalisation and exploring how we can engage further with UNAIDS Country Directors and regional directors on decriminalisation and country contexts, through a webinar or online meeting.
- Continuing our engagement in the finalisation of the Pandemic Instrument, including commenting on the zero draft.
- The Reference Group will consider, at the right time, to speak to WHO on their Framework for Engagement with Non-State Actors (FENSA) and the definition of state/non-state actors.
- Reviving the working group on access to medicines, with UNDP in a coordinating role.