

# Defining an AIDS Advocacy Agenda for a new era

Communities coming together, COMMUNITIES DRIVING CHANGE!

## REPORT PHASE 1

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# Defining an AIDS Advocacy Agenda for a new era

Communities coming together, COMMUNITIES DRIVING CHANGE!

REPORT PHASE 1 (internal)

## 1. Overview and background

- This project was designed as a follow-up to the launch of the ICASO Board CALL TO ACTION (May 2023). It was the first step in a process that culminated with a meeting of critical global and African advocates at the International Conference on AIDS and STIs in Africa (ICASA) in Zimbabwe.
- This report outlines the key activities and their respective results and provides potential activities for follow-on phases.
- This phase was made possible thanks to the support of the Global Fund to Fight AIDS, tuberculosis, and Malaria.
- Although financial support only covered ICASO to undertake this first phase, the phase itself was conceived to be part of a process. The follow-up and next steps depended on the meeting outcomes with global and regional advocates at ICASA. The follow-on phase has been designed to include a consultation process in other regions and a launch (or culmination of the development) of an AIDS ADVOCACY AGENDA at AIDS 2024 in Munich in July 2024.

## 2. Objective of this phase

To facilitate the participatory development of a global HIV advocacy agenda to influence and revitalize the global HIV response, ICASO will work with partners to undertake:

- A participatory process that involves key players from around the globe.
- An open discussion with a focus on advocacy priorities in ICASA 2023.

## 3. Team

This phase was co-coordinated by Michael O'Connor (Canada) and Ken Morrison (Mexico) with the assistance of Meena Sechu (India), Sophie Dilmitis (Zimbabwe), Olayide Akanni (Nigeria) and Talent Jumo (Zimbabwe) under the general supervision of Mary Ann Torres, ICASO Executive Director.

## 4. Activities Undertaken

1. Development of plan:
  - i. identification of potential partners, key informants, team players, and
  - ii. development of tools
2. Key informant interviews with global advocates

3. Online survey
4. Meeting in ICASA
5. Analysis and reporting

## 5. Results By Activity

### 1. Development of a plan, identification of key informants

The team collectively developed a workplan for the three months as well as identified key informants and potential partners, and, throughout the project, designed and adjusted tools as needed

#### EXPECTED RESULTS (from original plan)

1. Social mobilization of community groups, activists, and networks around a common agenda
2. Reinvigoration of the HIV response within a broader agenda on health and wellbeing
3. Greater focus on structural issues related to policy change, quality of services, community development, and measurement/tracking of those changes.

#### EXPECTED OUTPUTS (from original plan)

1. Questionnaire for stakeholder interviews (T=25)
2. A survey in four languages
3. Draft discussion paper for ICASA
4. A proposed *road map* for developing a renewed AIDS activist agenda leading to 2024.
5. Plan for regional discussion groups

Note that, by and large, the expected outputs and results were achieved or surpassed (see below deviations from plan).

### 2. Key informant interviews of global advocates

We conducted 43 interviews: 36 key informant interviews with global advocates and 7 with sex workers in India (See Appendix 1: list of interviewees and Appendix 2: interview guide)

- Results:
  - i. The enthusiasm was widespread, and people thought this a timely endeavor
  - ii. The team prepared a summary analysis to inform the development of the survey instruments and the open discussion in ICASA. It outlines emerging trends, themes, and recommendations concerning reframing global AIDS advocacy.

### 3. Online Survey

- Survey - 7 questions, four languages, range questions, and demographic info (5 aspects)
- Launched: November and closed 30 December 2023.
- Number responses as of 30 December 2023: English 96, Spanish 84, French 9, Russian 9. (See Appendix 3: Overview and link to surveys)

- Results:
  - i. Allowed for input from a broad scope of persons/advocates
  - ii. Mobilization and gauge of interest
  - iii. Initial results are similar to what we heard from key informant interviews
  - iv. Particular trends:
    1. Demographics:
      - a. The majority were over 35
      - b. For English majority from East and Southern Africa; in French from West Africa ;and Spanish from Latin America (M @60%, F 35%, NB 5%)
      - c. Highest responders: PLHIV, GBM, women
    2. HIV response in jeopardy: definitely 48%, somewhat 42% (in French, more said not in jeopardy).
    3. Highest ranked issues: access to medication, laws and policies, gender inequality, poverty, weak infrastructure.
    4. Advocacy priorities: highest ranked: resources for the community, community at the center, integrating HIV, stigma reduction
    5. Need a re-energized advocacy response: yes, 98%
    6. The most relevant steps: integrating into broader health, integrating into social justice, addressing data gaps, coalition building, aligned collective advocacy, information, and technology.
    7. Key advocacy targets: country governments, local politicians, and funders (in French: religious and health workers).
    8. Allies: SRH and UHC advocates, health delivery personnel, and other diseases.

#### 4. Meeting in ICASA

- i. Number of participants: 30
- ii. Number of organisations represented: 27
- iii. General agreement with the emerging themes and issues
- iv. General agreement that ICASO was well placed to continue
- v. General agreement with the need to reach deeper into regions and local communities
- vi. Recommendation: stronger focus on consulting with youth advocates
- vii. Some indication of funding interest
- viii. Annexes 4 and 5: Note and documents sent to participants with agenda, Appendix 6: Attendance list; Appendix 7: Final PPT presented; Appendix 8: meeting report.

#### 5. Partnership building

- i. Identification of parallel and related processes

- ii. GF Global Advocacy Roadmap was released
- iii. UNAIDS Annual Report: Let Communities Lead -was released
- iv. One Love project by GNP+
- v. IPPF, ILGA, and partners initiative
- vi. Identification of some partners for the next phase (in some cases, for example, local partners such as Kenya sex workers network, regional partners such as W4GF, APCASO, or global networks such as IPPF, GFAN, GF-CRG platforms)
- vii. Preparation for the next phase of this initiative includes developing potential partnerships, exploring funding possibilities, and building bridges with other sectors.
- viii. Consider engaging communication experts to help frame the advocacy priorities in the most relevant and appealing way.

## 6. Deviations From The Original Plan

Mini consultation in India

- i. To feed into the process from a particular subset in a specific place
- ii. To identify issues with farming out some simple instructions for feedback in preparation for the follow-up phase
- iii. Concurs largely with the findings of the key informant interviews

## 7. For Follow Up

These are some of the activities suggested for follow-up:

- 1. Regional, national, and community consultations
- 2. Key informant interviews with related issues exploring agenda overlaps –TB, NCD, climate, SRHR, pandemic preparedness
- 3. Meetings and communication with other processes-- Attend relevant meetings to present findings and seek buy-in from key stakeholders
- 4. Pre-conference meeting
- 5. Organize meetings at AIDS2024 (workshop?)
- 6. Launch and dissemination
- 7. Roadmap for implementation

## APPENDIX 1: GLOBAL KEY INFORMANT INTERVIEWS

	Name	Org
1.	Cheikh Traore	independent
2.	Brent Allan	independent
3.	Robin Gorna	Frontline AIDS
4.	Claudia Ahumada	Global Fund
5.	Fionnuala Murphy	Frontline AIDS
6.	Keren Dunaway	ICW
7.	Javier Hourcade Bellocq	GF -Communities' Delegation
8.	Ivan Cruickshank	CVC
9.	Andrew Spieldenner	MPACT
10.	Birgit Poniatowski	IAS
11.	Andy Seale	WHO
12.	Meena Seshu	SANGRAM
13.	Oswaldo Rada	Senderos Asociación Mutual
14.	Kevin Osborne	independent
15.	Anurita Bains	UNICEF
16.	Shaun Mellors	ViiV
17.	Raminta Stuikyte	independent
18.	Erika Castellanos	GATE
19.	Lynette Mtinkulu-Eyde	UNITAID NGO delegation
20.	Cleiton Euzebio de Lima	UNAIDS
21.	Nina Schwalbe	Spark Street Advisors
22.	Sofie Dilmitis	Global Fund Developing country NGO delegation
23.	Ángela León Cáceres	W4GF
24.	Mike Podmore	Stop AIDS
25.	Midnight Poonkasetwattana	APCOM
26.	Ivan Varensov	independent
27.	Katy Wright	GFAN
28.	Aditia Taslim	INPUD
29.	Othoman Mellouk	ITPC
30.	Florence Anam	GNP+
31.	Martha Clara Nakato	Alliance Uganda
32.	Amaranta Gomez	IIWGHA
33.	Maximina Jokonya	Y+
34.	Alvaro Bermejo	IPPF
35.	RD Marte	APCASO
36.	Group of young sex workers in India	

## APPENDIX 2: INTERVIEW QUESTIONS for global key informant interviews/partners

Note that these would be adapted according to the constituency of the person interviewed:

Introduction:

Explain background,

- ICASO Retreat: Call to Action
  - Explain process envisioned: INTERVIEWS to ONLINE SURVEY to ICASA
  - Depending on funding and interest: to define a process including REGIONAL and COMMUNITY consultations leading to Munich IAC 2024
1. Do you agree with the statement of the ICASO Board of Directors concerning developments threatening the sustainability and safety of ongoing activism around HIV? *(NOTE include the statement "Call to Action" with letter).*
  2. Although the global response to AIDS has seen many successes, do you see the current response to be in crisis?
    - If yes what needs to change to have a more robust HIV response from the point of view of your community or constituents?
  3. Is there a need to reshape the global AIDS Advocacy agenda?
    - If yes, could you provide 3 key priorities for advocacy from the point of view of you community
  4. How might we improve global advocacy?

Depending on the organization

Underscore ICASO would like to work with partners on this

- Do you have initiatives that feed into this process?
- Depending on the person, Would you be available for such things as to:
  - i. Validate and ground the assertions by the ICASO board
  - ii. Develop a consensus view and action agenda to be validated at the ICASA,
  - iii. Thoughts on process and expected results
  - iv. Lead a consultation process in 2024 (if funding) with your constituents

Get input on some of the following (depending on interviewee)

- Global unity amongst divers communities
- Thematic Focus of AGENDA
- Links to broader health and social issues
- Building leadership
- Links to Climate change
- Coordination of agenda development
- Communication related to agenda development and launch



## APPENDIX 3: ONLINE SURVEY

### Defining a new AIDS activist agenda for a new era

Since the beginning of the AIDS pandemic, community activism has consistently been the engine of the AIDS response, indispensable for driving political commitments, resource allocations, community development, and non-discriminatory legal frameworks needed to end AIDS. Recent developments threaten the sustainability and safety of ongoing activism related to HIV, its social determinants, and structural enablers.

ICASO is working with its partners to explore the current state of activism and advocacy related to HIV based on its recent [Call to Action](#). It is time to regroup, reexamine, and formulate a new agenda prioritizing saving lives and fostering wellbeing.

We invite you to take part in this participatory process to sound out the global community through this online survey, available in multiple languages. With the results of this survey, regional discussions, and key informant interviews, we hope to develop a consensus around a new global HIV advocacy agenda at the International AIDS Conference (AIDS 2024) in Munich. Your input to help build a re-invigorated HIV advocacy movement is much appreciated. Please share this survey with community colleagues and activists. Note that the responses will be kept anonymous.

<https://es.surveymonkey.com/r/HZWMMTY>

### Definiendo una nueva agenda de incidencia política contra el sida

Desde el comienzo de la pandemia del sida, el activismo comunitario ha sido el motor de la respuesta, indispensable para impulsar los compromisos políticos, la asignación de recursos, el desarrollo comunitario y los marcos jurídicos no discriminatorios necesarios para poner fin al sida. La situación actual a nivel mundial amenaza la sostenibilidad y la seguridad del activismo en curso relacionado con el VIH, sus determinantes sociales y los facilitadores estructurales.

ICASO está trabajando con sus asociados para explorar el estado actual de la incidencia política relacionada con el VIH sobre la base de su reciente [Llamado a la Acción](#). Es hora de reagruparse, reexaminar y formular una nueva agenda que priorice salvar vidas y fomentar el bienestar.

Te invitamos a participar en este proceso participativo para sondear a la comunidad global a través de esta encuesta en línea, disponible en varios idiomas. Con los resultados de esta encuesta, las discusiones regionales y las entrevistas con informantes clave, esperamos llegar a un consenso en torno a una nueva agenda mundial de promoción del VIH en la Conferencia Internacional sobre el Sida (AIDS 2024) en Múnich. Agradecemos mucho su contribución para ayudar a reconstruir un movimiento de incidencia revitalizado. Por favor, comparta esta encuesta con colegas y activistas de la comunidad. Tenga en cuenta que las respuestas se mantendrán en el anonimato.

<https://es.surveymonkey.com/r/HZ2YHJN>

### Établir un nouvel agenda militant de réponse au VIH pour une ère nouvelle

Depuis le début de la pandémie de sida, l'activisme de la communauté a toujours été le moteur de la riposte au sida, et un élément indispensable pour stimuler les engagements politiques, l'affectation des ressources, le développement communautaire et l'adoption des cadres juridiques non discriminatoires nécessaires pour mettre fin au sida. Or de récents développements menacent la durabilité et la sécurité de l'activisme actuel concernant le VIH, ses déterminants sociaux et ses facilitateurs structurels.

À la lumière de son récent [Appel à l'action](#), l'ICASO travaille avec ses partenaires à examiner l'état actuel de l'activisme et du plaidoyer en matière de VIH. Il est temps de se regrouper, de réexaminer la situation et d'établir

un nouvel agenda qui donne la priorité à la mission de sauver des vies et de promouvoir le bien-être – un agenda qui soit fondamentalement défini par les communautés et qui réponde aux facteurs mondiaux qui influencent chaque sphère de la vie des gens.

Nous vous invitons à prendre part à ce processus participatif pour sonder la communauté mondiale, par le biais de la présente enquête en ligne offerte en plusieurs langues. Grâce aux conclusions de cette enquête, de discussions régionales et d'entretiens avec des informateur(-trice)s clés, nous espérons parvenir à un consensus concernant un nouvel agenda mondial pour le plaidoyer sur le VIH, lors du prochain Congrès international sur le sida (IAC 2024) à Munich. Votre apport à la relance du mouvement de plaidoyer sur le VIH est très apprécié. Prière de relayer cette enquête à vos collègues et à des activistes communautaires. Veuillez noter que les réponses resteront anonymes. <https://es.surveymonkey.com/r/CCH29DB>

Определение новой активистской повестки для противодействия СПИДу в новую эпоху  
С самого начала пандемии СПИДа гражданский активизм является движущей силой противодействия СПИДу, незаменимым элементом формирования политической приверженности, распределения ресурсов и создания недискриминационных правовых рамок, необходимых для прекращения СПИДа. Недавние события ставят под угрозу устойчивость и безопасность активизма в области ВИЧ/СПИДа, его социальных детерминант и структурных факторов.

ICASO работает со своими партнерами над изучением текущего состояния активизма и адвокации в связи ВИЧ/СПИДом, основываясь на своем недавнем Призыве к действию. Пришло время заново объединиться, пересмотреть и сформулировать новую повестку дня, которая приоритизирует сохранение жизней и содействие благополучию. Повестку, основы которой определяют местные сообщества, но которая также учитывает глобальные факторы, влияющие на все сферы жизни людей.

Мы приглашаем вас принять участие в этом процессе с широким кругом участников, чтобы узнать мнение глобального сообщества с помощью онлайн-опроса, доступного на нескольких языках. Используя результаты этого опроса, региональных дискуссий и интервью с ключевыми информантами мы надеемся достичь консенсуса по новой глобальной повестке адвокации в области ВИЧ/СПИДа на Международной конференции по СПИДу (IAC 2024) в Мюнхене. Мы ценим ваш вклад в создание возрожденного движения адвокации в области ВИЧ/СПИДа. Пожалуйста, поделитесь этим опросом с коллегами из сообществ и активистами. Обратите внимание, что ответы будут анонимными.

<https://www.surveymonkey.com/r/P86FHJV>

## APPENDIX 4: BACKGROUND DOCUMENT SENT TO ICASA MEETING INVITEES

*Reframing the AIDS activist agenda for a new era  
Discussion document – DRAFT  
Please do not quote or share.  
1 December 2023*



### Reframing the AIDS activist agenda for a new era

#### Background

In April 2023, the Board of Directors of ICASO (The International Council of AIDS Service Organisations) met to take stock of the global response to HIV and, in particular, the state of community organizing in a greatly changed political, social, and epidemiological environment. Concerns were summarized in the [Call to Action](#)

*We believe that the lack of robust civil society engagement and oversight is key to explaining why the global AIDS response is faltering, particularly in terms of stagnating financial resources. AIDS is, de facto, no longer a global priority, and the consequences of this neglect are mounting.*

*It is time to regroup and formulate a new agenda, one that prioritizes saving lives and fostering well-being, one that is fundamentally defined by local communities while also addressing the global factors that influence every sphere of people's lives. It is time to build on existing alliances and create new partnerships to address intersecting health and social issues effectively to end AIDS for good.*

*ICASO seeks to continue partnering with other global, regional, national, and local organizations and networks to establish a platform for communities to strategize around these issues. The [International Conference on AIDS and STIs in Africa \(ICASA\)](#) in Zimbabwe in December 2023 provides one such opportunity to convene. Additional opportunities should be identified, and ICASO stands ready to work with civil society and community partners to rejuvenate the AIDS activist movement aligning with our changing world.*

ICASO has developed this brief document as background information in support of a discussion session hosted by ICASO and Katswe Sistahood at the International Conference on AIDS and STIs in Africa (ICASA 2023 to:

- Validate the assertion that the HIV response is in jeopardy.
- Discuss if the global AIDS advocacy movement needs to be re-energized. And if yes, why and how? If the world has changed and the HIV movement has changed, how does our advocacy need to change? Which bridges do we need to build, and which tactics do we need to adopt or let go of?
- Examine the advocacy priorities specific to the African region that must be front and center in global discussions.

The document summarizes comments from over 40 key informant interviews with global, regional, and national networks and organizations involved in HIV. This initiative will complement and augment similar reframing initiatives such as the Future of the AIDS Movement led by the Global Network of People Living with HIV (GNP+).

The discussion at ICASA is the first of what hopefully will be similar discussions in other regions, culminating at the 2024 International AIDS Conference in Munich (AIDS2024).

## General conclusions from the key informant interviews

### 1. PROCESS FOR CHANGE

**GOOD TIMING/IMPORTANT INITIATIVE:** There is general agreement that it is time to step back and reflect on what is needed to improve the current HIV response. Most acknowledged that progress in the HIV response has been historical but that the context has changed, complacency has set in, and it is time for another sense of urgency to push for change. Many agreed that the next five years are crucial. How do we keep HIV on the political agenda and access resources to reach agreed global goals? The number of people newly infected and not enrolled in treatment is increasing. We risk losing the gains made and a resurgent pandemic within shifting health and development priorities.

*Now is the time to dream together and not throw chairs at each other.*

**PROCESS OF REFLECTION:** In trying to provide a space to update the global advocacy agenda, many noted that we need to pay attention to process, product, and impact. This means that the process needs to be inclusive of the diversity of HIV community voices and needs. Everyone agreed that a global dialogue leading to consensus on an advocacy agenda was essential. One of the critical lessons of HIV is that *one size does not fit all* and that an agenda is only relevant if it is developed and owned by communities. A post-AIDS2024 process that includes developing regional advocacy action plans was suggested as a way forward. Most everyone noted that it is time for critical self-evaluation: time to ask difficult questions as we are often "*addressing new challenges with old solutions.*" Questions for further discussion included advocacy for what change? What is community? What does community representation mean? Is the existing global architecture/infrastructure (UN, resources, community networks) still fit for purpose?

*Money is disappearing fast, global custodians of the AIDS response are getting slapped in the face.*

**LANGUAGE AND CHANGE:** There were divergent opinions on the language of the process of improving advocacy. This included discussing the verbs *reinvigorate*, *renew*, and *revise*: there was general agreement that it is time to *review* and *update* HIV global advocacy. This will include a concerted effort to examine the broader advocacy ecosystem, considering the growing power and sophistication of anti-rights movements. Maintaining a focus on HIV while embedding it in broader social issues is the challenge the movement faces. Some noted that advocacy was often interpreted as confrontational and, in many countries, advocacy is about negotiation, providing evidence, and 'quiet persuasion'. There was some discussion around whether the movement is in 'crisis'. The common view was that the HIV movement is suffering from generalized confusion and a lack of common direction.

*AIDS is not going to be ended by 2030—HIV will be a reality for a long time, what do we do now and beyond, is crucial*

## 2. DIRECTIONS FOR CHANGE: A reframed advocacy agenda needs to be:

**SMARTER:** The HIV community must build on lessons learned: What works? How it works? Why it works? How are we responding to critical challenges in the current and future HIV response? An advocacy agenda needs to 'connect the dots' and understand and address intersecting systems. At the same time, it needs to identify priorities in the short term while working toward broader, longer-term objectives, including the Post2030 Agenda. Almost all agreed that an agenda must have concrete expected results and means of measuring progress. Many noted the need to rethink how we are organized and work together at the global, regional, and local levels. The process should provide a framework for reflection and accountability.

*The way in which we organize has to fundamentally change.*

**BOLDER:** While change can be difficult, it is not the enemy. We need to be bolder - more creative, explorative, innovative, and intentional with measurable results. The HIV response has always functioned on the edge of social change, pushing boundaries, addressing gaps, developing feedback and response systems, and working together to achieve results based on hard-fought priorities. Several noted the need to embrace technology and new social media communications tools. Many pointed out that the community must improve mechanisms for monitoring accountability of governments, global institutions, and ourselves. Many felt that the HIV response, for example, needs to use political mechanisms more effectively. Some mentioned the need to understand better and counter anti-rights and anti-gender movements (who build support with the pretext of being under threat). Many noted the importance of community-led monitoring but lamented that the work is often ignored or not entirely rooted in communities. Community-generated data needs to be gathered, understood and used systematically in decision-making and in setting priorities.

**MORE INCLUSIVE:** Creating and implementing a renewed advocacy agenda needs to be built around a process of social mobilization and linking to existing and emerging initiatives. Many mentioned that we often talk to ourselves in the current environment: preaching to the converted. We should connect people, provide opportunities for dialogue and self-examination, identify common goals, and work together on achievable results. *"The HIV movement can't change this situation on its own; we need to be honest about it"*. For the HIV community, this will include not only celebrating achievements but also embracing humility and a willingness to step back, listen, and learn. Solidarity and fostering a critical mass are essential. This will require building relationships with others, negotiating, and agreeing on collective goals. It will require increased funding and other resources to support creativity and innovation. Most interviewees noted three key elements: to reinvigorate the HIV response, we need to include young people, harness community evidence and concrete examples of change, and support existing human resources to be more adaptable to change.

*Responses are stuck in historic ways of working and have become mundane—what happened to the frank and fearless AIDS advocacy?*

## APPENDIX 5: NOTE SENT TO ICASA INVITEES AND AGENDA

Dear friends,

We are looking forward to meeting with you in the next hour at **the Monomotapa Hotel, 54 Park Lane, Harare, 6 - 9pm.**

We would like to start on time which means that all of **you will need to leave the Rainbow Towers by 5:30pm** at the latest given the traffic which should not be bad given that you will not be going against traffic, but please leave enough time to get to the Monomotapa Hotel by 6pm.

We are on the **first floor** the name of the room is **Ophir.**

You have two options:

- Either take a taxi which should not cost you more than \$5 or
- Walk - it's a 20 and a 30 minute walk (1.5 km) via Park Ln. Please see below a map from the Rainbow Towers to the Monomotapa Hotel

<i>Time</i>	<i>Agenda Item</i>
18:00 – 18:15	Arrival
18:15 – 18:30	Welcome and introductions
18:30 – 18:35	Why we are here and process
18:35 – 18:45	Present the findings from the interviews
18:45 – 19:00	Questions and Answers
19:00 – 19:40	Dinner & discussion on 3 questions: 1) Validate or not the premise that the HIV response is in jeopardy? 2) Discuss if the global AIDS advocacy movement needs to be re-energized. And if yes, why and how? If the world has changed and the HIV movement has changed, how does our advocacy need to change? Which bridges do we need to build, and which tactics do we need to adopt or let go of? 3) What advocacy agenda items specific to the African region must be front and center in global discussions?
19:40 – 20:20	Desert and plenary discussion
20:20 – 20:40	Other initiatives focusing on AIDS advocacy
20:40	Wrap up & next steps
20:50	Thank you & Closing



## APPENDIX 6: ICASA ADVOCATES MEETING ATTENDANCE LIST

CCM and TB RCM rep	Tariro Kutadza	Zimbabwe
DAHTPeople with disabilities (2)	Mr Tafadzwa Maseva	Zimbabwe
EANNASO	Mlewa Kalama Onesmus	Tanzania
GALZ	Tadios Munyimani (Teddy)	Zimbabwe
Global Fund (2)	Linda Mafu and Vuyiseka Dubula	Geneva/SA
GNP+	Omar Syarif	Netherlands
ICASO	Michael O'Connor	Canada
ITPC	Innocent Liason	Senegal
JAA	Olayide Akanni	Nigeria
Katswe Sisterhood	Talent Madzvia	Zimbabwe
LVCT Health	Patriciah Jeckonia	Kenya
MPACT GLOBAL	Matt Blinstrubas	USA
NSWP and KESWA	Nicole Oduya	Kenya
PAPWC	Tendayi Westerhof	Zimbabwe
SAT	Mildred Mushunje	South Africa/Zim
Real Change Fellow	Bernice Kalumba	Zambia
TBD	Paul Kavumbula	Zambia
UNAIDS	Chris Mallouris	GVA/RSA
UNICEF	Anurita Bains	USA
UNITAID CFP	Wim Vandeveld	RSA
UNITAID NGO Delegation	Carol Nawina	Zambia
ViiV	Shaun Mellors	South Africa
W4GF	Ángela León Cáceres	Ecuador
WHO	Meg Doherty	Switzerland
WLHIV (ICW East Africa)	Lilian Mworeko	Uganda
Youth Engage	Nicholas Niwagaba	Uganda

## APPENDIX 7: PPT FOR ICASA MEETING



# Exploration of Global HIV Advocacy within current contexts

Findings and recurring themes  
from interviews and online survey

Prepared by ICASO for ICASA Community Advocacy Meeting

## Background

- ICASO Board Retreat A Call to Action
  - Recognition of changing conditions and current contexts for responses to HIV
- ICASO allocated a small budget to:
  - Validate assumptions in Call to Action
  - Take the pulse of partners in the movement
  - Consider and articulate common themes and possible future actions
- Oct to Nov ICASO carried out interviews with 40+ community activist/organisers, and launched 4 language online survey (about 200 replies as of Dec 6)
- Today's gathering is the first time to share information gathered including recurring themes
  - It's *broad-brush strokes* meant to facilitate discussion and debate



## Interviewees Said

### 1. YES, GOOD TIMING FOR REFLECTION AND

- TIME TO STEP BACK, review the HIV response and work together to reframe advocacy
- NEXT FIVE YEARS WILL be CRITICAL: looking toward 2030 and beyond and post UHC priorities
- OPPORTUNITIES: Use upcoming events to bring together community to explore advocacy and build a shared agenda for review at MUNICH AIDS 2024.

### 2. COME TOGETHER TO FIND COMMON GROUND

- SUCCESSES: ACKNOWLEDGE and celebrate our successes, but adapt according to shifting priorities
- INCLUSIVE REFLECTION reach out to new allies and support new voices--and interests (In order to avoid *Same People Talking To Each Other*)
- Critical SELF EXAMINATION and accountability

### 3. SUPPORT ACTION-BASED ADVOCACY

- ACTION IS LOCAL even in global advocacy: How do we learn from and support local action?
- COMMUNITY-LED MONITORING: Learning to evaluate and improve through better monitoring and analysis
- UNAIDS REPORT: "Let Communities Lead": dovetails well with what interviewees said

## COMMON ADVICE: DIRECTIONS FOR CHANGE

- BE BOLDER
  - INNOVATE: Build on past AIDS activism experiences and work together to push boundaries creatively, while being responsive to changing situations including UHC, climate change etc.
  - INTENTIONAL: articulate clear concrete goals and steps to achieve them,
  - ACCOUNTABLE: Demand accountability for ourselves, our leadership, our governments
- BE SMARTER
  - STRATEGIC: Advocacy that is grounded in local experience and backed by locally generated data
  - SYSTEMS: Improved use of intersecting systems analysis – responding to people's lives experience and social conditions not just the biomedical needs that get most of the resources
  - COMMUNICATIONS: Update messaging and communication techniques to be accessible and provide feedback loops from communities
- BE INCLUSIVE
  - BRING PEOPLE TOGETHER: Advocacy as process of social mobilisation: opportunities for dialogue and for collaborative action
  - DIVERSITY: Recognise and embrace diversity in our ranks (between and within KPs) while collectively focusing on common priorities and needs
  - BUILD ALLIANCES: working in silos is over --reach out to new partners: young people, advocates from other overlapping movements such as gender equality, social justice, human rights, and health equity

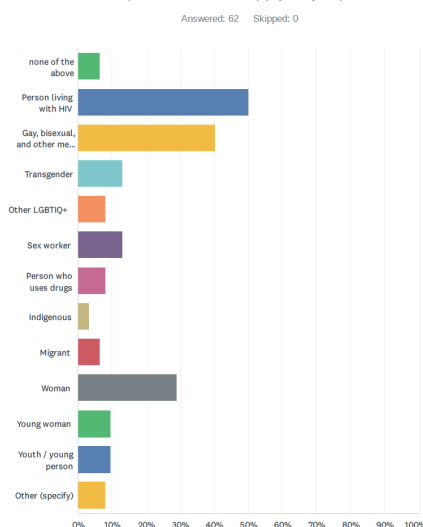
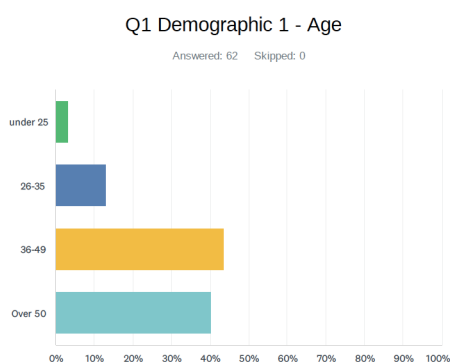
## EMERGING THEMES FOR ADVOCACY

- **INTEGRATION AND SPECIFICITY**
  - How do we strengthen health systems while maintaining the progress and specific needs of key populations for HIV
  - Connecting the dots to find commonalities or “thoughtful convergence” for broad collective action
  - Measured outreach with achievable results of common priorities
- **ACCESS TO SERVICES**
  - AIDS Is not over – we need a new push to reach an end – but keep a focus on “ACCESS TO Services” and quality of life
  - HIV biomedical response has given us amazing tools but the next phase needs to focus on health equity, enabling environments and social justice
  - Services need to include prevention, information, and better linkages to related health issues (TB, Malaria, NCDs)
- **COMMUNITY AT THE CENTRE**
  - “Meaningful involvement” is central and investment should recognise this.
  - Locally-driven advocacy – community monitoring and policy input systems and accountability
  - Better data collection to argue the value of community responses not just the biomedical tools

## Online Survey Preliminary Results —Dec 6

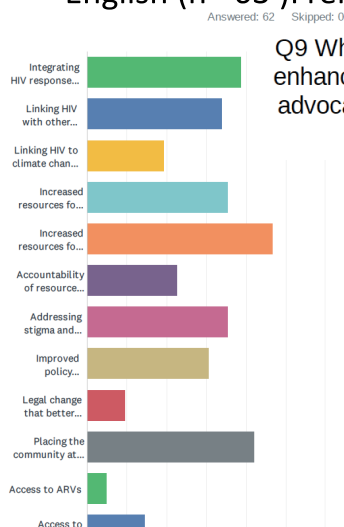
Q5 Demographic 4 - Key and vulnerable population with whom you identify  
(choose all that apply to you)

- English (n= 63 )



## Online Survey Preliminary Results—Dec 6

- English (n= 63 )French (n= 9) Spanish (n= 78) Russian (n= 9)



Q9 What are the three key (most relevant/urgent) advocacy priorities for enhancing a robust HIV response in your country/community? (Note that advocacy is any action that argues for, supports, or defends a cause. In this case, the cause is a more effective HIV response)

ANSWER CHOICES	RESPONSES
Integrating HIV response in broader health and well-being agenda	38.71% 24
Linking HIV with other social justice causes	33.87% 21
Linking HIV to climate change responses	19.35% 12
Increased resources for overall HIV response	35.48% 22
Increased resources for community-led activities in the HIV response	46.77% 29
Accountability of resource allocation	22.58% 14
Addressing stigma and discrimination of key populations	35.48% 22
Improved policy environments and decriminalization of issues such as HIV transmission, sexual diversity, gender diversity, sex work, drug use	30.65% 19
Legal change that better enables community-led HIV responses	9.68% 6
Placing the community at the center of the HIV response	41.94% 26
Access to ARVs	4.84% 3
Access to prevention commodities and information	14.52% 9

## Online Survey Preliminary Results —Dec 6

- English (n= 63 )French (n= 9) Spanish (n= 78) Russian (n= 9)

Q14 How do you improve accountability and inclusion for an enhanced and more effective advocacy agenda? (Use your own words in a few key phrases: max 30 words).

There is need to interrogate data collected within facilities and see best gaps within can help improve services. Our data can speak alot, and can be area that can provide reach information that can increase accountability and inclusion

To strengthen advocacy, it is crucial to establish transparent accountability mechanisms. Encouraging active inclusion through diverse consultations and regular evaluations maximizes program effectiveness.

Improving accountability can be strengthened by fortifying civil society role and capacity in community led monitoring. For enhancing inclusion it is important to make special provisions for the inclusion of highly marginalised groups that may not have the necessary skills and confidence to participate fully in decision making processes.

Le Plaidoyer budgétaire, la surveillance communautaire, participation active et la redevabilité.

En produisant les évidences qui montrent clairement les lacunes dans l'accès, la disponibilité et la qualité des services de santé. Celles-ci seront les informations stratégiques à mettre en exergue.

## Questions and Answers

### DISCUSSION

- Is the global response to AIDS in jeopardy?
- Do these initial findings correspond to our common realities?
- How do we re-energized the AIDS movement If the world has changed and the HIV movement has changed, how does our advocacy need to change? Which bridges do we need to build, and which tactics do we need to adopt or let go of?
- What advocacy items and priorities specific to the African region need to be front and centre in global dialogue, action and investment?

## APPENDIX 8: ICASA MEETING REPORT

### Reframing the AIDS activist agenda for a new era Report on consultation at ICASA: 7 December, 2023, Harare, Zimbabwe

#### Background

Community activism has been the engine of the AIDS response, indispensable for driving political commitments, resource allocations, community development, and non-discriminatory legal frameworks needed to end AIDS.

ICASO is working with partners to explore the state of HIV activism and advocacy, building on its [Call to Action](#). It is time to reexamine and formulate a new agenda prioritizing saving lives and fostering wellbeing. In October 2023, ICASO initiated a process to consult partners on the future of AIDS activism. The project allowed ICASO to conduct close to 40 key informant interviews and launch a multilingual online survey.

#### About the meeting

ICASO and Katswe Sistahood co-hosted a three-hour informal discussion with African community leaders and key partners that gathered for the International Conference on AIDS and STIs in Africa (ICASA). Thirty people participated in the meeting, representing global, regional, and local key populations (KP), gender, HIV and other networks, UN agencies, some donor organizations, and the Global Fund.

The participants received the report summarizing the key informant interviews both as a pre-read and as a presentation and were asked to comment on the following questions:

- Is the global response to AIDS in jeopardy, and do these initial findings correspond to our common realities?
- How do we re-energize the AIDS movement? If the world has changed and the HIV movement has changed, how does our advocacy need to change? Which bridges do we need to build, and which tactics do we need to adopt or let go of?
- What advocacy priorities specific to the African region must be front and center in global dialogue, action, and investment?

Participants largely agreed with the observations of the key informant interviews and noted that additional input for youth and more granular input from community groups are needed. They agreed that ICASO is well placed to continue facilitating this initiative, working closely with partners.

This report summarizes the meeting discussion and outlines the next steps. The rich discussion is captured in the following three sections:

- Articulating community contributions beyond AIDS
- The evolving world in which we live and work
- Looking to the future

## Key discussion outcomes

### 1) *Articulating community contributions beyond AIDS*

#### **Redefine the narrative, focusing on our significant contribution to UHC.**

Instead of focusing on the shrinking fiscal and civil society space and the lack of interest and commitment to end AIDS - we, the global community, should begin to articulate more positive narratives around the lessons and the leverage we have in our reach and response. No organization only works on HIV anymore – civil society and communities are delivering so much more and have become significant contributors to universal health coverage (UHC) and health systems strengthening (HSS).

**RECOMMENDATION:** The role played by the AIDS community in delivering health for all and ensuring no one is left behind, particularly the most marginalized and vulnerable, is a crucial part of UHC and needs to be asserted.

#### **Communities at the center**

Since the beginning of the pandemic, communities of people living with HIV have rallied around [meaningful engagement and inclusivity](#). We recognize the value of resilient communities as a central tenant to sustainable health. *Nothing About Us Without Us!* It is a good sign that UNAIDS has recognized and articulated this as *Let Communities Lead*. It is too easy to be rhetorical about this often-articulated statement. *Communities at the center* is a good slogan, but we are now having conversations in a vacuum and not seeing any authentic action leading to communities leading.

**RECOMMENDATION:** We need to develop alliances with other movements and begin to articulate common themes in support of each other.

#### **Accountability**

While international funding mechanisms like PEPFAR and the Global Fund (which expands civic space) are essential – they are also flawed and unsustainable. Given the state of the world, foreign funding streams will end sooner than we think. Can we count on our governments to step up? How can we enable this? And how can we hold them accountable? How can we hold international funders accountable and decolonize the donor/recipient paradigm? What are we doing to ensure Global Fund and PEPFAR funding (among others) is being allocated to end AIDS?

**RECOMMENDATION:** Develop a robust, transparent accountability mechanism to guide the transformations needed to ensure international funding mechanism remain relevant and effective.

### 2) *The evolving world in which we live and work*

#### **Building stronger pro-rights and pro-gender movements**

Human rights and gender equality are at the core of all AIDS programs. The right-wing anti-rights, anti-gender movements are successful when they confront us and isolate us in our silos. We must stand together across networks and interests to overcome these well-resourced, sophisticated, and oppressive movements.

**RECOMMENDATION:** Standing together in solidarity should not be dependent on funding. We need to resist being pitted against each other and fighting over pitiful amounts of money when the truth is that all of our collective work is important.

### **Our work has changed.**

Many of us got engaged as activists in the early days of the AIDS pandemic. Often, our advocacy work has morphed into service provision. Given that most of the world is no longer living in a state of emergency around HIV, the lack of urgency means we sometimes have less time for activism. Most funding available for communities is project-based. Given the volume of work, many champions have had little time to pause and reflect. Given the competition for limited funding, it was acknowledged that some AIDS activists have become gatekeepers - protecting their- piece of the pie - to ensure the sustainability of their networks and organizations. As

a result, we often find ourselves drawing away from colleagues - sharing less instead of working out better ways to work together. In the process, we become isolated from others. Having worked primarily in silos, many of us are perhaps deficient in contextualizing issues and working collaboratively across concerns and constituencies such as SRHR, climate change, and other health concerns, including non-communicable diseases (NCDs).

**RECOMMENDATION:** Now is the time to expand connections and engage with other health agendas: SRHR, human rights, gender, climate and across affected communities. Engagement with other communities can be undertaken in a way that builds solidarity and does not undermine the specificity of the AIDS response.

### **Poor donor environment and reporting**

There was consensus in the room that donors have lost interest in HIV, with their attention shifting to wars, the effects of migration and the climate crisis, and national right-wing agendas. While the HIV response has contributed substantially to health and community systems strengthening, we have not necessarily articulated and communicated this message very well. As stated before, organizations multitask and only report on the indicators they need to track. They are not reporting all the work they do on the side, that happens because they are part of the community. We saw this in COVID lockdowns when communities pulled together to help each other - when HIV and TB community networks were engaged in promoting vaccines and testing and addressed misinformation. We often under-report because donors focus only on their indicators.

**RECOMMENDATION:** Our value in the global health ecosystem is currently not visible and must be better tracked, described and valued.

### 3) Looking to the Future

#### **Be smarter and more strategic.**

Early in the HIV epidemic, "access to treatment" was our common advocacy focus. But what is our vision now? We have not developed long-term plans for where to be in ten years. We are reactive, not strategic. Do we believe that the 95/95/95 targets are relevant, or are we more concerned about the missing 5%? Can we develop a long-term shared vision and set targets to achieve it? How do we give local affected communities a better say in their focus? The window is closing for AIDS funding, and the landscape is changing, particularly regarding the future of global health initiatives discussion and the rollout of new treatment and prevention options like PrEP and MNRA vaccine.

**RECOMMENDATION:** We need a new 'hook' to reinvigorate the HIV response - to capture global attention and rejuvenate momentum. Participants were reminded that AIDS is still the leading cause of death in 14 countries, but in many parts of the world health care providers focus on NCDs. For HIV we need a way to get our movement re-energized and rally behind - just as the new vaccines have done for the malaria response.

#### **Young people and life today are different from early AIDS activism.**

The response to HIV and AIDS has evolved, and advocacy approaches that were needed in the past may no longer be relevant. Because of the historic success of the AIDS movement - many young people today have grown up in a world where people with HIV don't die, where treatment is available, and there are prevention options. They don't know the pain of the past. Young people do things differently and are growing up in a very different world and so much of this revolves around technology. Young people embrace a new set of social media tools that must be part of the AIDS response. The AIDS movement needs to do more to embrace new technologies and update its messaging to reach and be relevant to young people. At the same time, participants also spoke about the fact that - as with many other movements - some activists have become the 'old guard.' We must find ways to embrace a new generation of activists, build bridges, and agree on messaging across sectors. Working in silos is over, and young people need to be supported to lead.

**RECOMMENDATION:** Better acknowledge the activism of the past and mentor the next generation of leaders. Suggestions to address facilitate the 'handing over the baton' and usher in a new era of advocates included to facilitate possibilities or mentoring, and documenting the history of the AIDS response and to better recognize and acknowledge the work that has been accomplished.

#### **Learning from our mistakes**

Many echoed the sentiments that while we have so much to share - we also need to say that not everything has worked. Poor programming and working in silos led to missed opportunities. For example - why test only for HIV in a community when testing for hypertension, diabetes, STIs, HPV, and hepatitis could also be offered? Funding and reporting in silos caused this sort of inefficiency. The AIDS community could be more intentional and person-focused.

**RECOMMENDATION:** Let us share where we know we got it wrong and advocate for a comprehensive package of services for everyone and every subgroup could help but at the core is the principle that everyone has the right to wellness.



### Decolonizing the health response<sup>1</sup>

Participants called for urgent action to decolonize the health response. This means different things to different people, but participants spoke about the fact that often decisions are made for people in the global south by 'white men in the north'. We need to look at health initiatives and donor systems without the cultural and social impacts of colonial-era violence, racism, and misogyny.

**RECOMMENDATION:** It would be important to start having conversations about what decolonizing the health response would look like. Both the donor/recipient inequality as well as the lack of accountability between governments and their citizens, organizations and their constituents should be included in these discussions.

### Self-care

Activists give a lot to realize our gains; however, are sometimes drained and unable to self-care. Donors are not necessarily interested in investing in this area. Acknowledging and supporting the mental health of community activists and organizers is as important as supporting the programs they deliver.

**RECOMMENDATION:** Broaden the scope of HIV programming to take into account the needs of activists and leaders to ensure they are able to sustain their efforts.

### Aging with HIV

Participants noted that HIV advocacy has not yet taken on issues related to the impacts of taking HIV drugs for long periods. For example, women living with HIV experience menopause differently and sooner than women who do not live with HIV. We need to prioritize research on aging with HIV.

**RECOMMENDATION:** Increase exploration of aging with HIV and develop appropriate strategies.

### Next steps

The next steps for this process could include the following:

- Summarize the results of the online survey and relaunch if appropriate
- Reach out to critical donors to request support for the next phase of this initiative, which could include:
  - Create a multistakeholder advisory group to guide this process
  - Conduct additional targeted consultations hosted by communities and/or issue-specific regional and local networks.
  - Organize additional key informant interviews with climate, SRHR, and NCD communities to build bridges.
  - Facilitate a workshop at AIDS2024 to define an AIDS advocacy agenda
- Keep the networks engaged in any further actions as this all moves forward.

<sup>1</sup> For more information please see Kwete, X., Tang, K., Chen, L. *et al.* [Decolonizing global health: what should be the target of this movement and where does it lead us?](#)