

ILF THEMATIC ROUNDTABLE ON KEY POPULATIONS

24 February 2015

Seattle, Washington, USA

Meeting report





ACKNOWLEDGEMENTS

This report is the outcome of a thematic roundtable organized by the International AIDS Society's (IAS's) [Industry Liaison Forum \(ILF\)](#) and [Key Populations Priority](#) in Seattle, USA, on 24 February 2015. The ILF would like to extend its gratitude to the body of experts and key informants who participated in this meeting and provided invaluable insight and feedback.

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SUPPORT

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BACKGROUND

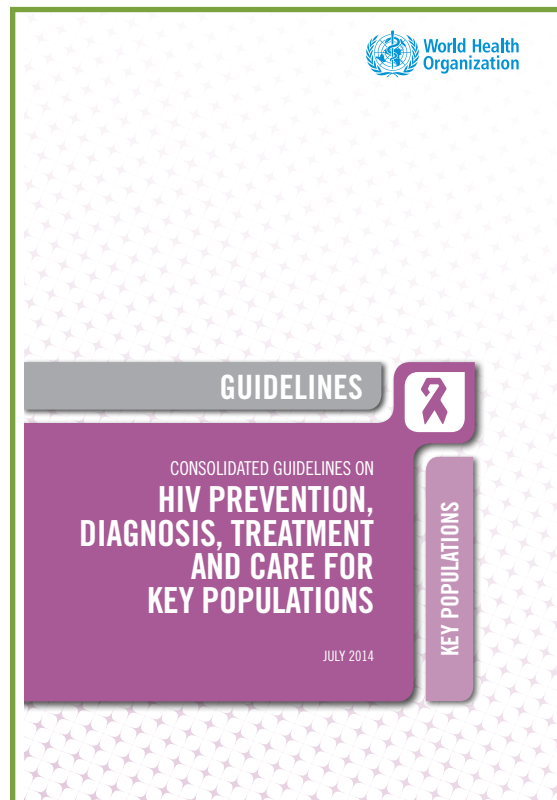
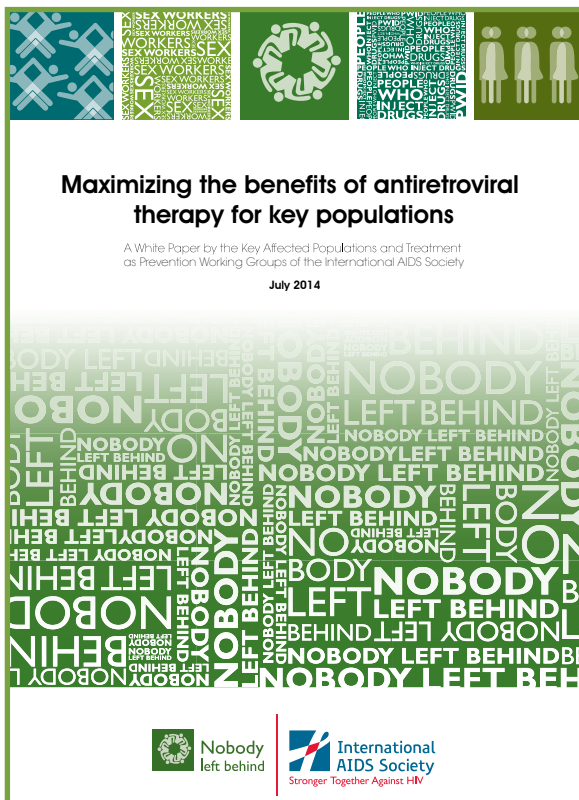
The International AIDS Society (IAS) has prioritized health care equity for key populations (often referred to as KPs) as one of its four major initiatives (the others are HIV co-infections, paediatric HIV and HIV cure). The IAS's Industry Liaison Forum (ILF) was developed to constructively engage industry and other stakeholders on issues in line with these priorities.

Industry has often been left out of discussions around key populations. However, industry plays vital roles in addressing the needs of people living with or at risk of HIV through the development of life-saving medication, essential diagnostics and prevention tools. It also has expertise in working with governments and international agencies to ensure that their products are accessible. Looking at emerging questions about reaching the "90-90-90" UNAIDS goals by 2020, it is clear that the global response to HIV will benefit from more engagement of industry partners around the challenges faced by key populations.

On 24 February 2015, the ILF held a thematic roundtable on key populations in Seattle, USA, to bring together a diverse group of experts from a range of backgrounds to discuss topics relevant to HIV where a multi-stakeholder approach, including industry, may lead to new and innovative solutions. Background documents for the meeting included the IAS publication, "Maximizing the Benefits of Antiretroviral Therapy for Key Affected Populations" and the World Health Organization's "Consolidated guidelines on HIV prevention, diagnosis, treatment and care for key populations".

The forum included keynote and "rapid fire" presentations from representatives of major key population groups and industry, among others, along with a wide-ranging roundtable discussion and debate. Participants learned about and discussed the issues and challenges and then drew together collective wisdom and recommendations for the way forward to meet the "90-90-90" goals for key populations.

This report synthesizes the discussion and outcomes of the meeting in a format that highlights themes and recommendations rather than the chronological order of presentations. It honours the open and frank spirit of the meeting by not attributing comments or ideas to individuals. All the points captured here were made in the meeting and are reproduced as faithfully as possible.



This very worrying trend highlights the critical need for the global HIV and AIDS community to identify what must change in strategy. The following are some of the key issues:

- Each group has unique needs and challenges. Within groups, there are sub-issues, often tied to geographical context, requiring a systematic commitment to tailored and responsive approaches.
- Traditional exclusion of key populations from an active role in policy, decision making and service delivery has led to continued lack of trust in, and cooperation with, mainstream services.
- In a difficult funding environment, support for new approaches will require that tough decisions are made about what existing suboptimal services should be cut.
- Advocacy strategies have to be updated for effective intervention in hostile policy and legal environments.
- Acceptance of the vital role to be played by a “more granular approach” to engagement of key populations in controlling the epidemic seldom aligns with global strategy and funding policies that tend to be blind to the sub-groups. Budget allocation is never proportionate to where the burden exists.
- There is no across-the-board agreement on the composition of key populations, and this lack of a unified position could undermine progress while debate continues. In particular, young people and women are insufficiently catered for despite bearing a highly significant burden of the disease
- Much is already known about what works and what is needed to end the epidemic. Why these strategies are not being properly put in place and supported has to be understood and addressed.

MEN WHO HAVE SEX WITH MEN

HIV treatment for ALL



“My body, my mind, my rights”

PEOPLE WHO INJECT DRUGS

HIV treatment for ALL



“My body, my mind, my rights”

SEX WORKERS

HIV treatment for ALL



“My body, my mind, my rights”

TRANSGENDER PEOPLE

HIV treatment for ALL



“My body, my mind, my rights”



KEY POPULATION GROUPS AND SUB-GROUPS: UNIQUE NEEDS AND ISSUES HIGHLIGHTED AT THE MEETING

MSM

“No one has best practices. Everyone is failing.”

The global prevalence of HIV among MSM is still high, and in some cases, the gains of previous years are being lost. It is known that community participation is needed; however, this still does not occur to the extent required.

A large number of MSM are unaware of their HIV status. Stigma and criminalization of homosexuality in more than 80 countries continue to work against changing this.

Differences within the MSM community demand different approaches. For example, disparities in income and health care coverage between black and white MSM in the USA mean a significant difference in the HIV cascade pattern and outcomes.

PEOPLE WHO INJECT DRUGS

“People get nervous about new drugs [medicines, for treatment and prevention] and have trust issues.”

Some of the key prerequisites for improving services for PWID include the transformation of punitive drug laws and ending criminalization of PWID, along with tackling the human rights violations and restrictions that go with these.

There are a number of best-practice examples where services are run by PWID themselves, strengthening the evidence for greater commitment to community engagement strategies and opportunities for education and employment in the sector. For example, PWID could be: trained as paralegals, participating in monitoring and evaluation; involved in policy and programme design; supported to run self-help groups; and lead organizations as peers.

Greater emphasis is needed on such areas as collecting sex- and age-disaggregated data, increasing access to evidence-based harm-reduction services, and removing barriers to access to services for young people and women who inject drugs.

SEX WORKERS

“There’s no working with sex workers without involving them in the process.”

By far the highest burden on sex workers is in sub-Saharan Africa.

Prevention is a particular challenge for this group, and it remains a human rights issue. Sex workers are highly discriminated against, and the effectiveness of the response for this group cannot be improved without addressing structural constraints.

The focus with sex workers should be on community empowerment and meaningful participation within the broader context of a human rights framework. This has to mean more than “a few peer educators and a drop-in centre”. It is also helpful to involve wider stakeholders in the process, including the police and judiciary.

It is not easy to build social cohesion in the sex work industry. Ways must be found to demonstrate to sex workers that they are more powerful together.

TRANSGENDER PEOPLE

Allow us to be contributing in ways other than sex work, so we can contribute to our own wellbeing ... Hire us first!”

Trans women are the key population that bears the biggest HIV risk, not “trans people”. In fact, trans men might experience a less-than-average burden. It is therefore important to focus on trans women when discussing this group in relation to HIV.

Trans women suffer in terms of having their particular needs recognized and met, even from within the global HIV and AIDS community, due to a tendency to place them as a group with MSM, including in data collection in many areas.

In addition to stigma and discrimination as a result of transgender status (which is true for all transgender people), trans women are also discriminated against as women. Their crossover with sex workers as a group has to be teased out given the high prevalence of sex work among trans women.

Health care providers require additional education to provide appropriate support and, very often, trans women find themselves teaching their health care workers how to support them. HIV-positive trans women face some unique issues in their health care and the interaction of drug therapies with hormone treatments. Not enough is known yet about the impact of newer approaches, such as pre-exposure prophylaxis (PrEP), and insufficient research is being done.

Trans women need to have greater access to employment within the HIV/AIDS sector and also to be more represented on such bodies as the Global Fund’s Country Coordination Mechanisms to ensure that their voices are heard.

ACROSS THE KEY POPULATION GROUPS: YOUNG PEOPLE

“We call for change, we are part of that change.”

Young people in each of the key population groups experience a high percentage of the disease burden, and in some cases, it can even be greater than that of the adult population. For example, in the Asia-Pacific region, young people aged 15-24 years constitute 40% of new HIV cases, and of these, 95% are from key population groups. Despite this, only 10% of budgets in this region are devoted to programmes targeting young people.

Young people face many additional barriers to access that are specific to their age group, such as requirements for either parental consent or to be married to access sexual and reproductive health services. In addition, harm-reduction programmes tend to only cater for adults. Priorities include establishing youth-friendly services, obtaining meaningful youth participation and engagement, addressing the legal barriers, and establishing comprehensive sex education and capacity building.

OTHER KEY POPULATIONS

WOMEN AND YOUNG WOMEN

“HIV prevention methods for women are an urgent unmet need.”

There are widespread examples of where particular female groups share the same characteristics and challenges as other key population groups. For example, young pregnant women in South Africa are an especially high-risk group, and female sex workers in sub-Saharan Africa are vastly overrepresented compared with any other region.

Young women can often be overrepresented compared with adult women. For example, in India, prevalence of HIV among female sex workers aged 16-20 years is more than three times the prevalence among adult women sex workers.

Choice of prevention method is critical for young women and can vary within the group. In the same way that women require a variety of contraceptive choices, a flexible approach is also required with HIV prevention.

MEN IN PRISON

The prevalence of HIV in male prison populations compared with the general population varies, but is generally significantly higher. In some cases, such as in Ukraine and Mauritius, it can be 15 to 20 times higher and more.

Only eight countries provide needle and syringe exchange programmes in prisons.





MORE TO BE DONE...

1. Change in the policy environment

As noted, a number of current shifts and developments may have a negative effect on access to and by key populations, especially when combined. The bulk of the key population groups, with some geographical exceptions, face existing criminal laws, and in many countries, also face waves of new laws that directly or indirectly increase pressure on them. For example, anti-homosexual laws in Russia have seen the disappearance of anonymous support services for HIV-positive MSM. Criminalization of sex workers' clients in Sweden and new laws in the USA criminalizing HIV transmission are also having a ripple effect. Added to this tightening environment is the shift toward biomedical prevention as a central treatment approach, which is strengthening a fear of coerced testing. The combination of these factors can only present increasing challenges to outreach and testing programmes as key population groups become less open to participating in testing or treatment.

A central dilemma for the HIV/AIDS sector is therefore how to move forward when best practice relies on lifting criminalization at a time when there is little appetite for doing so in many places. Cohesion in advocacy was highlighted as more important than ever, as was the quest for ways to:

"reach people with the tools that they deserve and they have a right to, even in bad environments ... and we have to try to change those environments." ¹

2. Data and research

Data collection and research are not yet keeping up with demand for finely detailed information, particularly about key populations. Early indicators in HIV data collection were narrowly focused, and the consequent lack of detailed longer-term information is a problem that the sector itself has created.

Key population groups can be difficult to access or to gain their cooperation through traditional means. Sex workers, for example, are a group who are particularly underrepresented in data sets, while they shoulder high risks, high burdens of the disease, and still have overall low access

to services. Very few studies have enough sex workers in them for stratified analysis.

Factors such as stigma and discrimination towards key populations have not been taken seriously enough in data collection to date, being seen more as "soft outcomes". These are, however, critical elements in overall outcomes that can, for example, explain disparities such as those between numbers of PWID diagnosed and those on antiretroviral therapy (ART). It is proposed that an increased focus be placed on social science methodologies in order to discover how to impact stigma and discrimination and to learn from the lessons of other sectors.

It cannot be assumed that all groups will respond to all interventions and products in the same way, in fact it is more certain that they will not. Courage is needed to find innovative ways to conduct fresh research on how to move ahead with these products (especially in the case of prevention). The keys to success for improved data collection include to be more strategic and to use methods that do not compromise people's safety.

"We have a lot of random acts of goodness, but we don't have a systematic plan or have it to scale."

Scalability and operational research, including how to scale up at speed are pressing issues. While there will always be many good ideas for small-scale pilot projects, this tends to lead to a wide array of disconnected evidence that is not moving the sector closer to its global targets. Big thinking is needed, but in a way that matches resources and what can be achieved. This also means having to cut or scale down other things, which is a difficult conversation in the sector.

While it is important on the one hand to "think big", on the other hand, key populations must be viewed and researched in great detail in order to capture the nuances and differences within the groups. There is little homogeneity within and across the groups, and an understanding of differences across age, gender, geography and other criteria must be kept in mind.

¹ The upcoming United Nations General Assembly Special Session (UNGASS) on the world drug problem, to take place in 2016, will be an opportunity to address the problematic policies for PWID.

LOOKING FORWARD

1. Ambitious targets

UNAIDS is setting a series of ambitious targets that apply to the cascade (the so-called “90-90-90” goals), HIV prevention and rights. The intention is to create a comprehensive set of goals that bring together the targets needed to end the epidemic.

“It is where we need to be getting to in order to drive down incidence and mortality and end the epidemic.”

The targets represent what has been found to be possible in model programmes. The challenge is to replicate these outcomes in other settings, and to do so in the face of insufficient funding to ensure their achievement. People are aware of the potential for these targets to either “reinvigorate the ambition” or to become “empty promises” if they are not followed with effective strategy, implementation and advocacy. There is room for optimism, however, and the inclusiveness of the targets provides a tool for much-needed advocacy to improve the visibility of key populations in national plans and their profile in funding models.

2. Rolling PrEP out

Although the IAS and others are advocating for the scale up of PrEP for all populations at risk, at the time of writing, it is only approved in one country (i.e., USA)² and the community is calling for a scale up of PrEP activities globally at a national level, including registration of the product (the combination of tenofovir and emtricitabine) for use as prevention in many more countries so that it can be deployed strategically and far more widely.

“We have an intervention but it’s not available to the people who need it.”

While PrEP has immense potential, specific issues related to some of the key population groups underscore the central theme of the roundtable: that there is a need to be aware of specific obstacles and to tailor strategy. For example, trans women may take a cautious approach until the potential interaction of PrEP with their hormone treatments is known.

On the other hand, a rising incidence of HIV among MSM in many countries may mean that acceptance and roll out move at a faster pace, but it will also necessitate rapid and large-scale evidence that PrEP is capable of halting the spread of the epidemic.

Tailored programmes should be designed to engage and work with the more reluctant groups (e.g., PWID). Overall, there may also be value in reassuring key population groups that a new focus on PrEP will not mean the loss of other support services.

“Come sit with us and then back us. Work with governments so that people don’t lose other services in place of this one (PrEP).”

3. Community engagement

“One needs to have the courage to allow solutions to come from within the group.”

Without dissent, community engagement with key population groups is seen as vital to making progress. There is recognition that despite good intentions and many good-practice examples, it simply has not happened broadly enough to date to have the impact required. Although there is agreement on the importance of engagement, groups currently have different perceptions of what it would look like in practice. It was acknowledged that:

“we need to do better in systematizing what that means and how to do it in more places.”

For some, community engagement means creating more roles in providing services. For others, it means empowerment. For some representatives of key populations, it means providing education, training and jobs in HIV programmes. It is proposed that solutions should come from within the key populations themselves, along with a commitment to listen to them more actively and facilitate the participation of those who are less skilled or confident. A renewed commitment to such an approach must be weighed against the knowledge that somehow following through with these convictions rarely happens to the degree needed and therefore strategies to

² At the time of writing, trials and demonstration projects are ongoing in a number of countries. However, the use of tenofovir and emtricitabine for PrEP remains approved only in the USA, although off-label practices exist in some countries.



sustain engagement and the momentum to do it must also be realized.

For groups seeking to reach community-based organizations, Viiv Healthcare's Positive Action programme can facilitate networking with members of its database of more than 2,000 community-based organizations for non-commercial projects that are aimed at supporting these communities or are planning to undertake legitimate scientific or social research.³

4. Service delivery models

Characteristics of successful programmes include that they adapt themselves to the client group, take a friendly approach, focus on retention and offer flexible hours and “turnkey” services. Development of choice in options of prevention, diagnostics and treatment (including formulations) is vital in

engaging disparate groups, and programmes should consciously target and tackle issues in the cascade to address barriers along the continuum of care.

There are many examples of good and successful practices in service delivery. However, learning is not being systematically applied and adapted. There is a strong feeling in the sector that:

“We have a lot of tools. We know what we should be doing but are not applying it systematically.”

This problem includes some actors' reluctance to back or sustain backing for marginal and innovative programmes that are designed and run by the key populations themselves. These groups encourage mainstream actors to “get out of their comfort zones and take risks” as loss of support for these programmes once they are established can have a range of negative consequences.

A good example of a multi-pronged and multi-faceted initiative is the Linkages across the Continuum of HIV Services for Key Populations Affected by HIV Project (LINKAGES), funded since 2014 by PEPFAR (through USAID) and implemented by FHI 360. It is aimed at conducting a range of activities across the HIV prevention and care cascade to reduce HIV transmission among four key population groups – MSM, PWID, sex workers and trans women – to improve their enrolment and retention in care. At the same time, it is aimed at helping key populations mobilize and advocate for changes in laws and the conduct of police, health care workers and policymakers, and work with governments to make programmes sustainable in the long term.

Other points were raised during the roundtable discussion relating to service delivery models:

- Implementation at the national level must include an understanding of regional differences. Programmes to scale up implementation should target regions that are likely to provide the greatest impact in outcomes in order to maximize the use of resources.
- In order to achieve sustainability and impact, services should be integrated within existing health systems. At the same time, services should be significantly decentralized to get them into communities and into key populations in particular.
- There is a critical role for new technologies, such as self-testing and point-of-care diagnostics, that communities can use and adapt, democratizing programmes. Programmes should “leapfrog” ahead to innovative models that will help reduce stigma and increase empowerment and community ownership. Regulations and testing models could change, for example, moving them out of doctors' offices.
- Finally, the sector should not just rely on national governments to adequately train and sensitize their health workers.

STRONGER TOGETHER AGAINST HIV

³ Individuals or organizations are invited to contact Manuel Gonçalves (manuel.a.goncalves@viivhealthcare.com) or Dominic Kempis (dominic.x.kemps@viivhealthcare.com) directly for any inquiry.

Appendix A: Agenda

THEMATIC ROUNDTABLE ON KEY POPULATIONS

Organized by the International AIDS Society's Industry Liaison Forum and Key Populations Priority

Tuesday, 24 February 2015, 18:30–22:00 PST • 2201 Westlake Avenue #200 (PATH), Seattle, WA, USA

18:30-18:45	Welcome and roundtable introduction Kenneth Mayer (Fenway Institute, USA) – ILF Co-Chair Manuel Gonçalves (ViiV Healthcare, UK) – ILF Co-Chair	
18:45-19:00	Overview presentation I: KPs – demographics, epidemiology and epidemic drivers Gottfried Hirnschall (WHO HIV/AIDS Department, Switzerland)	Facts
19:00-19:20	Overview presentation II: The cascade for HIV prevention, diagnosis and treatment in the context of discrimination Chris Beyrer (Johns Hopkins University, USA) – IAS President	Barriers
19:20-20:25	Panel discussion: Best current practices to reaching KPs Moderator: Kevin Frost (amfAR, USA) Panellist / PWIDs: Holly Bradford (INPUD, USA) Panellist / Sex workers: Frances Cowan (CeSHHAR, Zimbabwe) Panellist / Transgender people: JoAnne Keatley (UCSF, USA) Panellist / Young KPs: Thaw Zin Aye (Youth LEAD, Thailand) Panellist / MSM: Nikos Dedes (Positive Voice, Greece) Panellist / Diagnostics: Duncan Blair (Alere, Thailand) Panellist / Treatment: Paul Schaper (MSD, USA) Panellist / Prevention: James Rooney (Gilead Sciences, USA) Panellist / Prevention: Gustavo Doncel (CONRAD, USA)	Challenges
20:25-21:45	Roundtable discussion: Innovative approaches to meeting the 90-90-90 UNAIDS goals for KPs <ul style="list-style-type: none">• Programming and policies• Access to prevention, diagnostics, treatment and care• Stigma and discrimination• Financing and accountability• Technology Facilitator: Chris Collins (UNAIDS, Switzerland)	Solutions
21:45-22:00	Summary: Challenges and opportunities Kenneth Mayer (Fenway Institute, USA) – ILF Co-Chair Manuel Gonçalves (ViiV Healthcare, UK) – ILF Co-Chair Sébastien Morin (IAS, Switzerland) – ILF Research Officer	

Appendix B: List of participants (page 1 of 2)

PARTICIPANTS FROM INDUSTRY

ARV / originator	AbbVie	Jean Van Wyk – Medical Director, AbbVie Global Medical Affairs	ILF
ARV / originator	Gilead Sciences	James Rooney – Vice President, Medical Affairs	ILF
ARV / originator	Janssen	Peter Williams – Compound Development Team Leader	
ARV / originator	MSD	Paul Schaper – Senior Director, Global Health Policy	ILF
ARV / originator	ViiV Healthcare	Helen McDowell – Director, Government Affairs, Access and Patient Advocacy	
ARV / originator	ViiV Healthcare	Manuel Gonçalves – Vice President, External Affairs, Access and Communication	ILF
ARV / generics	Cipla	Jaideep Gogtay – Head, Medical Services	
ARV / generics	Mylan Laboratories	Emmanuel Patras – Deputy General Manager, FDF Sales Marketing	
Diagnostics	Alere	Duncan Blair – Director, Public Health Initiatives	ILF
Diagnostics	BioLytical Laboratories	Richard Galli – Vice President, Chief Technical Officer	
Diagnostics	Cepheid	* Philippe Jacon – Executive Vice President, International Commercial Operations	
Diagnostics	Omega Diagnostics	John Bannister – Director, Global Health Regional Sales	ILF
Diagnostics	Roche Molecular Diagnostics	Robert Luo – Director of Clinical Research, Virology	
Diagnostics	Roche Molecular Diagnostics	Tri Do – Global Head of Clinical Research	

OTHER PARTICIPANTS

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American Foundation for AIDS Research	Kali Lindsey – Deputy Director, Public Policy Office	
American Foundation for AIDS Research	Kevin Frost – Chief Executive Officer	
Asia Pacific Coalition on Male Sexual Health	* Matthew Vaughan – Senior Programme Officer	
AVAC	Mitchell Warren – Executive Director	
Bill & Melinda Gates Foundation	Ed Lee – Strategy Officer	
Bill & Melinda Gates Foundation	Gina Dallabetta – Senior Program Officer, Global Health Program/ HIV Programs	
Careena Centre for Health	Ava Avalos – Director	
Cayetano Heredia University	Carlos Cáceres – Professor and Director, Unit of Health, Sexuality and Human Development	
Centre for Sexual Health and HIV AIDS Research Zimbabwe	Frances Cowan – Executive Director	
Clinton Health Access Initiative	Carolyn Amole – Associate Director, Drug Access Team	

Appendix B: List of participants (page 2 of 2)

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Elizabeth Glaser Pediatric AIDS Foundation	Nicholas Hellmann – Strategy and Science Advisor	ILF
Fenway Institute	Kenneth Mayer – Founder, Co-Chair and Medical Research Director	ILF/GC
FHI 360	Nirupama Sista – Associate Director, Science Facilitation	
FHI 360	Timothy Mastro – Director of Global Health, Population and Nutrition	
Forum for Collaborative HIV Research	Veronica Miller – Executive Director	
Global Network of People Living with HIV North America	Anna Forbes – Consultant	
International AIDS Society	Owen Ryan – Executive Director	IAS
International AIDS Society	Rosanne Lamplough – Associate Project Manager, HIV Programmes	IAS
International AIDS Society	Sébastien Morin – Research Officer, Industry Liaison Forum	IAS
International Network of People who Use Drugs	Holly Bradford – Chair of the Board	
Istituto Superiore di Sanità	Stefano Vella – Head, Department of Therapeutic Research and Medicines Evaluation	ILF/GC
Johns Hopkins Bloomberg School of Public Health	Chris Beyrer – Director, Johns Hopkins Center for Public Health and Human Rights	ILF/GC
Johns Hopkins Bloomberg School of Public Health	Stefan Baral – Associate Professor and Director, Key Populations Program	
Kirby Institute	Andrew Grulich – Head, HIV Epidemiology and Prevention Program	GC
Office of National AIDS Policy	Douglas Brooks – Director	
Pangaea Global AIDS Foundation	Ben Plumley – Chief Executive Officer	
Partners in Diagnostics	Elliot Cowan – Principal	ILF
PATH	Grant Colfax – Program Leader, HIV/AIDS and Tuberculosis	
Positive Voice	Nikos Dedes – President	
UNAIDS	Chris Collins – Chief, Community Mobilization Division	
UNITAID	Robert Matiru – Portfolio Manager, HIV/AIDS	
University of California, San Francisco	JoAnne Keatley – Director, Centre of Excellence for Transgender Health	
WHO	Gottfried Hirnschall – Director, HIV/AIDS Department	
Youth LEAD	Thaw Zin Aye – Coordinator, Secretariat	

ILF ILF Advisory Group member

GC IAS Governing Council member

IAS IAS Secretariat

* Attended remotely through WebEx

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