## Healthcare

## Stigma-free services cookbook

Inspired by the real-life stories and advice from the champions celebrated through the Me and My Healthcare Provider campaign of IAS - the International AIDS Society - since 2016



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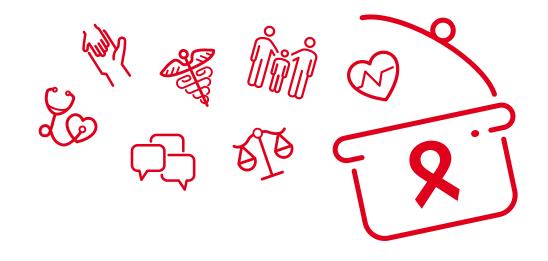
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## The history of this cookbook

#### What is the aim?

This "cookbook" aims to inspire ideas on how to provide quality, inclusive and stigma-free HIV services in any healthcare setting around the world. It is a book of ingredients that can be combined and transformed into an infinite number of recipes, recognizing that there are many ways to "do the right thing" in the face of stigma.

The aim of this book is also to celebrate courage. It is inspired by the real-life stories and advice from the champions celebrated through the Me and My Healthcare Provider campaign of IAS – the International AIDS Society – since 2016.

#### Who is it for?



The main audience for this book is healthcare workers, who may identify with and learn from the stories, challenges and triumphs it describes. Educators supporting the health workforce may also be interested in including this content in curricula and training to focus on quality and inclusive care that is free from stigma and judgement. Community activists and researchers working to reduce stigma may also find the content helpful in planning and evaluating interventions to eliminate HIV-related stigma in healthcare settings.

To learn more about the IAS Me and My Healthcare Provider campaign, please visit:

www.iasociety.org/me-and-my-healthcare-provider

#### Why is it needed?

## Stigma: A weak spot in the HIV response

According to the Global Partnership for Action to Eliminate All Forms of HIV-Related Stigma and Discrimination, the progress towards reaching the global 95-95-95 targets is significantly undermined due to stigma and discrimination and their negative impact on the health, lives and well-being of people living with or affected by HIV.

It is for this reason that UNAIDS has developed four global AIDS societal enabler targets for 2025, focused specifically on stigma and discrimination<sup>1</sup>. Related to healthcare settings, the 2025 target is that less than 10% of people living with HIV report internalized stigma or stigma and discrimination in healthcare and community settings.

Data highlight how HIV-related stigma is still common in healthcare settings. Across countries with available data:

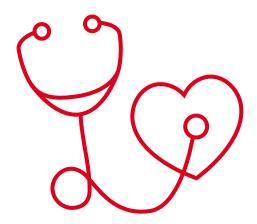
- Only six countries (of 23 with recent data) report less than 10% of people living with HIV experiencing stigma and discrimination in healthcare and community settings<sup>2</sup>.
- Up to 21% of people living with HIV report being denied healthcare in the past 12 months<sup>2</sup>.
- Up to 40% of people living with HIV report being forced to submit to a medical or health procedure<sup>2</sup>.

Discrimination can also be institutionalized in restrictive laws and policies, further entrenching stigma and discouraging people from seeking help<sup>2</sup>.

https://www.unaids.org/sites/default/files/media\_asset/07-hiv-human-rights-factsheetstigma-discrmination\_en.pdf

<sup>2.</sup> https://www.unaids.org/sites/default/files/media\_asset/global-partnership-hiv-stigma-discrimination\_en.pdf

## Why focus on HIV-related stigma in healthcare settings?



- https://www.unaids.org/sites/default/files/media\_asset/2022-global-aids-update\_en.pdf
- 4. Mulubale S, Clay S, Squire C, et al. Situating HIV Stigma in Health Facility Settings: A Qualitative Study of Experiences and Perceptions of Stigma in 'Clinics' among Healthcare Workers and Service Users in Zambia. Journal of the International Association of Providers of AIDS Care (JIAPAC). 2022;21. doi:10.1177/23259582221100453

- Like other societal settings, healthcare settings are not immune to stigma. Creating a stigma-free atmosphere in healthcare settings is key to providing life-saving treatment and services, particularly for young key and priority populations who face a double burden of stigma and for whom stigmatizing expressions and actions may have a negative impact on healthcare decisions<sup>3</sup>.
- Stigma in healthcare settings includes negative feelings, beliefs, attitudes and expressions towards people living with HIV<sup>4</sup>.
   It can also take a more tangible form, such as delays in treatment, differential or conditional care, neglect or refusal of service<sup>5</sup>.

https://www.unaids.org/sites/default/files/media\_asset/eliminating-discrimination-guidance\_en.pdf

# Ingredients for providing stigma-free healthcare services



"Get training in counselling and sexuality education, in addition to reflecting on your own stigmas."

**MMHCP** champion

#### For managers and health system planners

- Ensure that every facility has a reporting mechanism where an incident of stigma can be reported to ensure quality of care and solicit feedback.
- Follow up on any reports of stigma and implement a zero-tolerance policy for stigma in the workplace.
- Provide recognition and incentives for providers who "do the right thing" so they feel appreciated for their efforts.
- Enable training opportunities for continuing professional development about stigma and interpersonal concerns affecting clients, and provide practical opportunities to apply that learning in clinical practice.

#### For managers and health system planners

- Proactively seek feedback from communities and be responsive to any issues or suggestions raised.
- Be mindful of language, including in client intake forms and personal information documentation, to be inclusive of diversity and not make assumptions about sexual history, for example.

"Treat a person like a human, not as an anonymous number."

Javier Martínez Badillo

#### For healthcare providers

- Learn from and be inspired by champions from the Me and My Healthcare Provider campaign in the spirit of continued professional development and opportunities for growth.
- Listen to your clients. Observe and respond to the evolving dynamics of stigma in your context.
- Listen to communities for the most appropriate terminology that is stigma free in your context.

#### For healthcare providers

- Inspire your colleagues to provide stigma-free services and develop ways to educate your peers in response to any incident of stigma witnessed in your setting.
- Be mindful of language and be open minded and inclusive about client information, such as sexual history and recent behaviours.
- Be mindful of body language and other tacit communication signals that can welcome or repel clients from diversebackgrounds.

- (Continue to) do the right thing to provide quality services for all.
- Dare to hope for a more inclusive future free from stigma and be proud of your contribution to making those changes within the health system.

"Be sensible and listen to their experiences. Understand that living with HIV is more than just living with a virus because it modifies other areas of life."

Rodrigo Vázquez Venegas

#### For users of health services

- Report acts of stigma or discrimination experienced or witnessed in a healthcare setting.
- Give feedback to providers to encourage a change in approach or language.
- Appreciate and celebrate providers who do the right thing and provide stigma-free and quality care.
- (Continue to) lead by example within the medical profession.



## Advice for healthcare providers to provide services free from stigma

#### ✓ Do's

Listen first. ✓ Empathize. Be professional. Partner with people ✓ Keep privacy Anticipate what living with HIV in the stiama-free service and respect design of service provision looks and confidentiality. feels like. delivery. ✓ See a whole person ✓ Use sensitive and Understand the - more than a virus. open-minded client's human language rights. ✓ Understand stigma. ✓ Be self-aware and challenge your own stigmas.

#### × Don'ts

- Don't assume.Never blame.Don't judge.
- Never forget that people have feelings.Don't perso
- Don't bring in any personal feelings and perceptions.

## Stories from healthcare providers

"doing the right thing"





We asked healthcare champions about their motivations and to share their suggestions for inspiring others in scaling up stigma-free service provision. The stories and recommendations in the pages that follow are informed entirely by the champions' views and suggestions. Each story is unique, combining the ingredients outlined above and sharing their personal recipes for how to provide stigma-free healthcare services.

There's not just one recipe. There are many – but they all have three things in common:

- Empathy and a strong drive for professionalism
- The importance of really listening to clients and understanding what their needs are
- Feeling proud to serve clients and their diverse health needs in a holistic and non-stigmatizing way

Honest

Integrity

**Determined** 

#### Malawi

Project coordinator

15 years as a healthcare provider

### **Loveness Bowa**

I provide quality services by ensuring that all our drop-in centres are friendly for all communities and free from stigma and discrimination. I also ensure that a full range of services is available at the centres, such as HIV testing and access to treatment, screening for sexually transmitted infections, prevention of vertical transmission of HIV, contraceptive counselling and planning services, cervical cancer screening, and screening and support for sex- and gender-based violence. We also take services to harder-to-reach areas where there are no health facilities.

A turning point for me was when one female sex worker defaulted from accessing services and taking her treatment after being ill-treated by a health worker who showed a poor attitude towards her at the facility.

I am proud of removing barriers for people accessing healthcare services in my implementing districts (Zomba and Machinga). We have also now been certified as provision sites for key populations for antiretroviral treatment.

I am inspired by our Malawi Secretary for Health, Rose Nyirenda. She visited our centres (which was the first time in Malawi) to learn more and ensure that quality services are offered to all communities, including key population groups.

My hopes for the future are to ensure that punitive policies, which limit access of some communities to receive health services, are removed. I hope for all people to enjoy their rights.

**Empathetic** 

Resilient

Compassionate

#### Mexico

Programme coordinator

Healthcare worker for 5 years

### **Carlos Ahedo**

I studied a bachelor of nursing and midwifery and have a higher diploma in collective health and HIV.

My hopes for the future are to contribute towards the end of HIV – not only the biomedical aspects, but also the elimination of social stigma.

"My hopes for the future are to contribute towards the end of HIV."

**Empathic** 

Warm

Responsible

12 years as a healthcare provider

## **An-Chun Chung**

Stigma is always present in society, especially in infectious diseases and gender-related issues. I am proud of being a helper.

Empathy is the first thing in providing quality services. Equality and treating everyone the same is the second thing. Not evaluating someone's actions is the third thing. But it's not easy, and it takes time and self-awareness to develop these skills.

Every case inspires. It is magical to see and move forward together with an individual throughout their care. It is a miracle.

If I meet another provider who does judge or stigmatize, I would first seek to understand what they don't understand. I would speak to them in a language they can understand. If we give them some time, it will be different.

**Friendly** 

Honest

**Ambitious** 

#### **Botswana**

Healthcare worker for more than 13 years

## Neo Monnapula

My current role is to care for women. I am proud to be helping women, especially female sex workers, to live dignified, longer and healthy lives. I respond to clients' needs on time and provide all the necessary support, including referrals to other services. I also make sure to provide services that are free from stigma.

I seek to reduce stigma in my community by empowering female sex workers on human rights and helping them be aware of stigma and ways to confront it. I also share with other healthcare providers about the needs of female sex workers. If I witness another worker stigmatizing someone, I would tell them to see a person as a human being first and not judge. I would also let them know that if they do that, more people will be happy to access their services.

I am inspired by the women I serve. The women are resilient, open to sharing their journeys, and welcome ways that will improve their lives. I hope for a tolerant, flexible, progressive and loving society.

**Empathetic** 

Holistic

Hopeful

#### **Argentina**

Medical staff coordinator

More than 23 years as a healthcare worker

## **Romina Mauas**

I didn't learn about stigma as part of my medical training. It was only after my formal medical training and during my work with communities that I came to understand the global problem and try to fight against it.

I am proud to be empathetic and observe my clients empower themselves. I try to offer a holistic approach in how I provide services, integrating physical, psychological, socioeconomic and behavioural services.

I am inspired by good colleagues working in the field of HIV, especially people living with HIV who have such capacity for resilience and working together.

If I meet another provider who stigmatizes in their treatment of others, I would encourage them to treat others as they would like to be treated themselves. We are all human beings with the same rights. There is no need for social discrimination or marginalization due to age, race or ethnicity, gender identity, sexual orientation, socioeconomic status or HIV status.

My hopes for the future are to expand access to good-quality sexual and reproductive health services, enhance combined prevention, attain gender equality, and continue working on stigma-reduction interventions. I hope to keep building bridges between service providers and the community.

# Passionate

Innovative

**Explicit** 

Hong Kong, SAR of China

Public health practitioner for more than 20 years

## Wang Chen\*

\* To protect the identity of the champion, a pseudonym is used.

I didn't learn about stigma as part of my medical training. A real turning point for me was when someone I knew died by suicide after learning about his HIV diagnosis. Since then, I have decided to make an effort on this issue.

I always seek the client's view to inform how to provide quality services. I am proud to have been able to plan and implement a new HIV service. It takes time to change people's habits. I keep reminding other medical staff to use proper, neutral wording in conversations, health education materials and documents.

My hope for the future is that people living with HIV can be themselves and express themselves openly.

"My hope for the future is that people living with HIV can be themselves and express themselves openly."

Caring

Responsible

**Passionate** 

HIV case manager

Health worker for more than 18 years

## Ling-Ya Chen

Stigma and discrimination were part of my medical training. In my country, people who have a mental illness, are not heterosexual, are using illicit drugs or are living with HIV still face an ordeal when seeking medical care.

A real turning point for me was at college when I went to a stage show with some friends. The show was about HIV. I was shocked by how the protagonist was treated by the hospital staff. Now I try to stand with my clients and provide accurate medical and scientific evidence.

There are several role models in HIV care in Taiwan. There is one hospital director who is fearless and dedicated to providing the best care to people living with HIV.

My hope for the future is that people living with and affected by HIV will be treated like everyone else.

# Humanist

Empathetic

**Facilitating** 

#### Mexico

Clinical psychologist

Providing care for more than 7 years

## Esperanza Flores\*

\* To protect the identity of the champion, a pseudonym is used.

In my professional training, I was taught not to stigmatize people. That was a reaffirmation of my philosophy of life. Never forget that we are all people and that is what counts.

A pivotal moment for me was working face to face with one of my clients and seeing that I had the opportunity to help destigmatize their diagnosis. When they came back sometime later to tell me that they were undergoing treatment or undetectable, it really made me think that this is exactly where I want to be. I feel proud to be a woman who can do such a noble job and I feel lucky to be able to help people and see how they "turn poison into medicine".

I always try to be very sensitive and empathetic, especially for the communities I serve who are often deprived of liberty, homeless, migrants or sex workers. These communities need special attention; for example, often they do not know how to read or write and face other barriers to taking their treatment. I try to give everyone the same treatment. For those who require extra attention, I try to solve their concerns.

I think we need to start seeing ourselves as people more than as the one who has X or the one who is Y, and begin to see ourselves for what we are worth and our skills and what we can contribute to society.

I hope for equality. I hope that we are all seen as more than a diagnosis, a race, an economy class, and so on. I also hope for an end to wars and hunger in the world and an end to violence against women. Above all, I hope to leave my daughter a world where she has hope.

## Soi persond en mediar

Sensitive

Constant

Brave

#### **Mexico**

President, Red Mexicana

More than 34 years in healthcare

## Javier Martínez Badillo

A real turning point for me was when I treated a woman who had a deep sense of guilt and anguish when she arrived at the clinic because our society points at her and makes her feel vulnerable. There is guilt, there is anguish, and there are no opportunities. I asked myself what I would like in that situation. I also listened as people told me I could bring a little hope in the uncertainty.

In every case, I look for inclusivelanguage alternatives. I seek to look at who I see in the office and to be able to tell them that they are not alone. I am inspired by people who help. They leave a legacy – their passion, their foolishness, their ease of moving people and reaching hearts. They provide an example for my life. In my organization, there are also leaders with that passion. This gives me guidance and says that we are not alone.

**Dedicated** 

**Passionate** 

**Tired** 

#### Lebanon

Physician and assistant professor

Healthcare worker for 20 years

### **Nesrine Rizk**

I try to treat everyone with respect and appreciate the human in them and connect with the human to provide my medical care. I use my current position and role to educate and be a good role model (which is what I was taught about trying to give back).

A pivotal moment that informed how I seek to provide stigma-free services was learning from excellent humanist physicians and role models who were exemplary in dedication, respect and love for fellow humans.

"I use my current position and role to educate and be a good role model."



Compassionate

**Passionate** 

Hong Kong, SAR of China

Clinical psychologist

Working in healthcare for more than 7 years

## **Barry Tam**

I am proud of being a clinical psychologist and that I have the luxury of being able to sit with my clients in 50-minute sessions. I always find it fascinating to listen to their stories.

At the beginning of my career in serving people living with HIV, I noticed that people showed a sense of connectedness in their eyes when I tapped their shoulder or elbow to show support. I was shocked as it reflected how stigma has isolated them from society. I became even more determined to fight against stigma as I started practising narrative therapy, a treatment modality that emphasizes the exploration of an alternative yet preferred self-identity. Learning narrative therapy gives me an extra layer in understanding people that I see in my practice.

There is a senior doctor who inspires me a lot in my work. From observing his interaction with a client, I became cognizant of how to engage people who may find the healthcare system unwelcoming.

If I met a healthcare provider who had stigmatized someone in my facility, I would speak to them based on what I have observed, factually. I would also discuss how the person might feel and the consequences on their experience. I would encourage the provider to think about the reason behind their behaviour.

I hope to promote equal rights for people living with HIV.

**Patient** 

**Empathetic** 

Discreet

#### **Brazil**

Infectious disease specialist

Healthcare worker for more than 28 years

## **Demetrius Montenegro**

I have a bachelor's degree in medicine and completed a medical residency in public health and infectious diseases. I also have a master's degree in tropical medicine. Unfortunately, I did not learn about stigma or discrimination in my medical education. In fact, I learned about it in my daily life as a health worker, working with neglected diseases, such as filariasis and leprosy, and later with people living with HIV, seeing the reality of the prejudice suffered by people affected by these pathologies.

I live in a country with two realities: most people do not have a support network that helps them face all the stigma caused by HIV and [avoid] abandoning treatment or irregular use of therapy, which leads to resistance. This is the great challenge.

My greatest pride is when a client looks at me and says, "Thank you for listening

to me." I try to pay attention to people I treat, listen to them and look into each one's eyes. Providing quality services goes far beyond offering medication to offering a hand to give strength in difficult times.

I am inspired by the HIV response. I have hope for life and living the history of HIV in its different phases – from the time when there was no treatment to the present. It is this hope for life that inspires me. My hope for the future is about early diagnosis, support and zero prejudice against people living with HIV. It will take education and human respect to reduce stigma at scale in my context.

Responsible

Delivering

**Empathetic** 

#### **Mexico**

HIV healthcare provider

More than 10 years in healthcare

## Isis León Franco

When I was a student in medical school, the topic of HIV was still quite limited. Although we were taught to treat all service users equally, the topic of stigma was not covered.

It makes me proud to see my service users leave with a smile. It also makes me proud that in this facility, we are more than co-workers; we make a family. We all have hope and see a future ahead. What I am most proud of is being able to change the opinions of people with absurd and ignorant thoughts about HIV, who mistakenly think that with this diagnosis, one cannot work or have children.

In my consultations, you listen and do not judge. Clear words are used without technicalities. Reviews are respectful and treatment is cordial. On my shift, we are no different; we are all family. It is thanks to my service users that I continue on this path and accompany them in their fight.

Setting a good example starts at home. I have spoken with my daughters and my mother, and their perceptions of HIV are now different. They tell me that they speak in their schools or with the other family and that we have created a chain of accurate information. This information removes fear. By removing fear, we remove stigma.

I hope for there to be universal access to education because education is the key to having access to information. This, in turn, eradicates ignorance and in the end, like a chain of dominoes, the pillars of discrimination and stigma will fall.

# Confidential

Resourceful

Resilient

#### Jamaica

Communication specialist

More than 7 years in healthcare

## Patricia Marley\*

\* To protect the identity of the champion, a pseudonym is used.

I learnt about stigma by seeing firsthand the fear of accessing care some people experience because of the stigma and discrimination of their sexual orientation. The reality is that when our clients are not accessing care and are left to deal with their situations, it can be life-threatening and, in those instances, we have failed in our mission to provide holistic and optimal care for all.

I provide quality services by ensuring that confidentiality is maintained. I provide a safe space for all our clients to feel comfortable sharing what their problems are so that we can provide the best care. I am proud of being a behaviour change communication officer who can be a part of the change towards a better environment for healthcare.

If I witnessed another provider stigmatizing a client, I would remind them that it is important to be kind to one another and be understanding as these behaviours prevent people from accessing care or sharing information in confidence.

My clients inspire me the most because they are the ones we serve and it is our responsibility to do right by each of them in providing information on prevention, care and support.

My hope is to be part of the change to provide a better environment for healthcare workers and for clients to access stigma-free care at all public health facilities.

# Caring Dedicated Hard working

#### Jamaica

Adherence counsellor

Working in healthcare for 8 years

## Michelle Getten

My aunt died of AIDS-related illnesses 18 years ago, and our family was not educated very much about HIV back then. Stigma and discrimination were very high. As an adherence counsellor, I help my clients develop and understand their treatment and its challenges. I maintain privacy and confidentiality, which is important for reducing stigma. I just wish I was more educated then to assist my aunt.

I am proud when someone I am working with reaches viral suppression after they have been referred to me for not adhering to their medications and having a high viral load. This makes me proud of the work I am doing as an adherence counsellor.

My hopes for the future are to see people living with HIV and who are a part of the LGBTQ community access comprehensive care without fear.

**Persistent** 

**Hard working** 

Loving

#### Kenya

Linkage officer

Worked in healthcare for 7 years

## Daisy Kwala

I did learn a little bit about stigma in my education, but the real stigma is in implementation. Working with people who experience stigma each day in the community has made me understand the effect of stigma on healthcare. I have seen people dying because of issues that could have been prevented by just being stigma free and offering services to them.

I'm a health rights activist who works in the community to link communities most vulnerable to HIV to drop-in centres that are "friendly". I also do home visits and daily treatment for some clients. Together with our advocacy team, we have monthly stigma and discrimination sensitizations conducted in the community at police stations and other health facilities.

I am proud of many things. Changing lives every day motivates me, and I am proud of being approachable and enabling sex workers to reach out at any time for support. I am proud to have helped many sex workers living with HIV achieve viral suppression. I am proud of the children who have been born free of HIV. I am proud to be the change that I have been praying for.

I hope for a future with zero discrimination, where everyone is entitled to equal human rights and is supported in access to quality healthcare.

### Annex

## About the IAS Me and My Healthcare Provider campaign

The IAS Me and My Healthcare Provider campaign was established in 2016 to promote best practices in providing healthcare that is free of HIV-related stigma. The campaign recognizes frontline healthcare workers who deliver quality HIV prevention, treatment and care to communities most affected by and vulnerable to HIV. The campaign aims to build a better understanding of what motivates these healthcare champions to provide inclusive and stigma-free services, amplify their stories to encourage replication, and empower others to confront HIV-related stigma. The campaign is part of the broader engagement of the IAS on Getting to the Heart of Stigma, a portfolio of activities focused on reducing stigma in healthcare settings.

To date, six campaign rounds have taken place, organized annually. So far, 46 healthcare champions from 19 countries across Africa, Asia, Europe and Latin America and the Caribbean have been identified. This followed nominations received directly from their clients: people who are diverse and often marginalized, such as gay men and other men who have sex with men, sex workers and their clients, trans people, people who inject drugs and people living with HIV. The healthcare champions and their nominators have been honoured during award ceremonies at international conferences and/or locally and have taken part in activities aiming to inspire replication of practices that are free of HIV-related stigma.

#### **Definitions**

As defined by the <u>Global Partnership for Action to Eliminate all Forms</u> <u>of Stigma and Discrimination</u>, formed by partners in 2018:

**HIV-related stigma** is evident in irrational or fear-driven negative attitudes, behaviours and judgements towards people living with HIV, their partners and families, and key populations.

**HIV-related discrimination** is unfair and unjust treatment of a person, or group of people, based on their real or perceived HIV status.

**Key populations** are defined as groups who, due to certain higher-risk behaviours, are at increased risk of acquiring HIV. The IAS uses "key populations" to refer to gay men and other men who have sex with men, people who inject drugs, prisoners and other incarcerated people, sex workers and their clients, and trans people.

#### **Terminology guides**

Language matters. People living with HIV experience stigma and discrimination. The wrong language perpetuates stigma and marginalizes people.

The People First Charter was launched on 20 July 2021 during IAS 2021, the 11th IAS Conference on HIV Science, to promote person-first language in the field of HIV. It aims to ensure that our language matches our goals: that all people living with HIV are supported to enjoy the highest attainable standards of health, as is their fundamental human right. You can sign up to learn more about how to commit to the People First Charter and help promote the use of the right words in the right way. If you hear or see language that is not people first, please encourage the use of people-first terminology. Correct people kindly and gently, remembering that we all make mistakes and that it takes time to embed change.

UNAIDS also produces terminology guidelines.

The IAS would like to thank Gilead Sciences for their generous support to the Me and My Healthcare Provider campaign.





#### **About the IAS**

IAS – **the International AIDS Society** – convenes, educates and advocates for a world in which HIV no longer presents a threat to public health and individual well-being. After the emergence of HIV and AIDS, concerned scientists created the IAS to bring together experts from across the world and disciplines to promote a concerted HIV response. Today, the IAS and its members unite scientists, policy makers and activists to galvanize the scientific response, build global solidarity and enhance human dignity for all those living with and affected by HIV. The IAS also hosts the world's most prestigious HIV conferences: the International AIDS Conference, the IAS Conference on HIV Science and the HIV Research for Prevention Conference.