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البحث المجتمعاتي
يلبي احتياجات
الميدان.



A pesquisa também me
diz respeito !



La recherche
communautaire pour
transformer la
société.



La investigación
comunitaria
para transformar
la sociedad.



La recherche communautaire
répond aux besoins du terrain.

Community-based research in action!



La recherche
communautaire
répond aux besoins
du terrain.



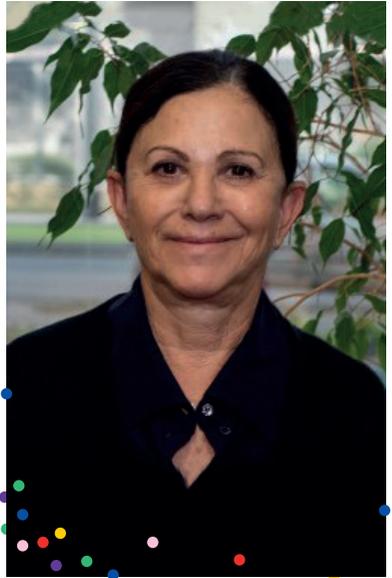
La investigación,
acortando
distancias desde la
comunidad

This brochure describes the involvement of Coalition PLUS member organisations in community-based research. Community-based research is an approach to research that is based on an equitable partnership between researchers and communities for programmes that are based on evidence and tailored to the needs of the people for whom they are intended. This document does not seek to exhaustively present all the community-based research conducted by the member organisations of Coalition PLUS, but rather, to merely present a diverse sample of the projects carried out since 2015 that, at the time of this document’s writing, have first results. These examples, spread across 6 research themes, reflect the priorities of action shared by Coalition PLUS that have a real impact on the HIV/AIDS and hepatitis epidemics: PrEP, testing, the right to healthcare for drug users, prevalence and incidence studies, access to healthcare, and living with HIV.

This second edition is an update of the brochure “Research by and for people living with HIV. Our community organisations are mobilising”, which was published in 2015.

We sincerely thank the participants of the research projects, the organisations that led them, the funding bodies who financed them, and our partners who placed their trust in us.







A letter from the Chairperson

Researchers, work with us, not for us!

The member organisations of Coalition PLUS are working every day for a world without AIDS or viral hepatitis through a multitude of research projects that extend far beyond the goals set by the international community. If 90% of people who live with HIV know their status, and if 90% of tested individuals are receiving a sustainable antiretroviral treatment, and if, finally, 90% of people receiving antiretroviral treatment have a sustainably repressed viral load (which is the goal for 2020), this nevertheless means that, unfortunately, 27% of people living with HIV, more than one in four, are not receiving proper care, or any care at all. All those who are not yet tested, who are not yet on treatment, or who are facing therapeutic failures constitute the dynamic epidemic, that of vulnerable key populations who, due to discrimination and stigmatisation, experience great difficulties in accessing testing and care. Finding innovative solutions to reach the 27% of HIV-positive individuals who do not have an undetectable viral load is essential to having a direct impact on HIV incidence. It is also the reason for our community-based research laboratory.

Our projects depend on the support and knowledge of our communities. In fact, when it comes to research, who better than individuals infected with and affected by HIV and hepatitis to increase our knowledge of this area? With regards to prevention, who better than those individuals who are the most exposed to help us formulate messages and implement tools that are the best adapted to avoid new infections? In terms of care, who better than those who live with these viruses to describe the difficulties in accessing medical care and to help us improve treatment adherence by sharing their own experiences? And what better engine for action than the testimonies and the anger and pain of those who have suffered the full brunt of stigmatisation and discrimination?

The key to success lies in our ability to act together. We must therefore support and reinforce the community-based research conducted within our organisations, which should no longer be considered simply as a means of reaching the most exposed populations, but rather as essential partners for developing and conducting research projects: AIDES in France, ALCS in Morocco, ANCS in Senegal, ANSS in Burundi, ARAS in Romania, ARCAD-SIDA in Mali, COCQ-SIDA in Quebec, GAT in Portugal, Groupe sida Genève in Switzerland, IDH in Bolivia, Kimirina in Ecuador, PILS in Mauritius, and REVS PLUS in Burkina Faso.

To bring about a world without AIDS or viral hepatitis, to go further than the 90-90-90 to reach the 10% of HIV-positive individuals who do not know of their serological status, the 19% who are not receiving antiretroviral treatment, and the 27% whose viral load is not sustainably undetectable, nothing about us without us¹!

Hakima Himmich

Chairperson of Coalition PLUS

¹ According to the Denver Principles, 1983.

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➔ The organisations that participated in the creation of this brochure



AIDES

- Founded in 1984, recognised as a public interest organisation in 1990
- 76 mobilisation sites
- 1,280 activists

www.aides.org



ALCS

- Founded in 1988, recognised as a public interest organisation in 1993
- 500 volunteers and peer educator coordinators
- 24 information centres with free, anonymous testing
- 5 mobile testing units

www.alcs.ma



ARAS

- Founded in 1992
- 5 centres in Bucharest
- 65 employees and 35 volunteers

www.arasnet.ro



ARCAD-SIDA

- Founded in 1994
- Active list composed of more than 51% of the people living with HIV (PLHIV) in the country
- 15 healthcare sites and 4 sexual health clinics

www.arcadmali.org



COCQ-SIDA

- Founded in 1990
- Group of 38 community-based entities fighting against HIV/AIDS
- The largest coalition in the fight against AIDS in Canada

www.cocqsida.com



GAT

- Founded in 2001
- 3 HIV support, care, and testing centres
- 49 employees

www.gatportugal.org



Groupe Sida Genève

- Founded in 1987
- 26 employees and 3,300 members
- The largest local Swiss aid office fighting against AIDS

www.groupesida.ch



IDH

- Founded in 1997
- Located in Cochabamba
- 23 employees and approximately 100 volunteers

www.idhbolivia.org



KIMIRINA

- Founded in 2000
- Located in Quito, Guayaquil, and 5 other cities in the country
- 10 community centres, 3 of which are in Quito

www.kimirina.org



PILS

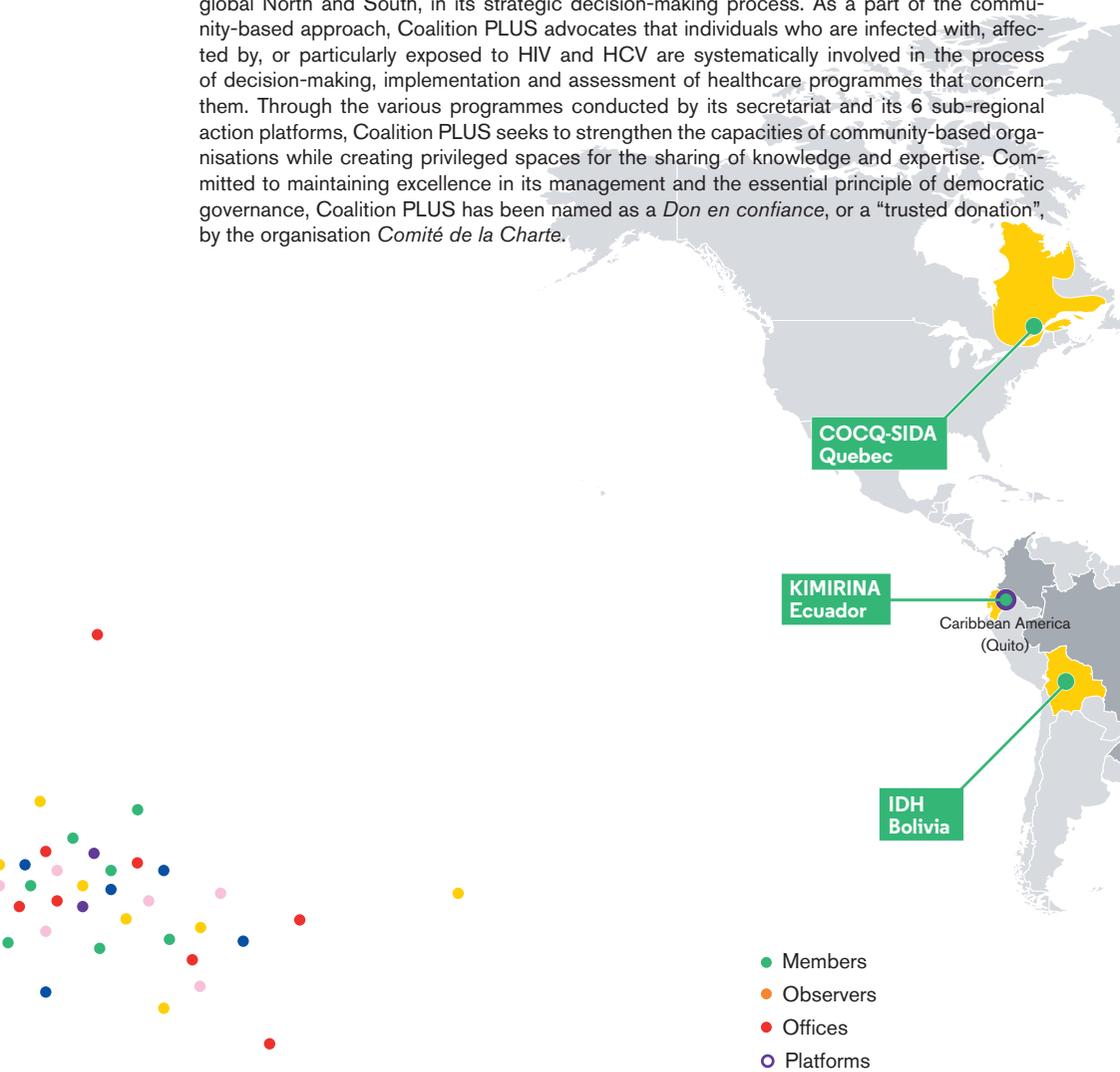
- Founded in 1996
- 33 employees
- Principal beneficiary of the Global Fund to Fight AIDS, Tuberculosis, and Malaria since 2010

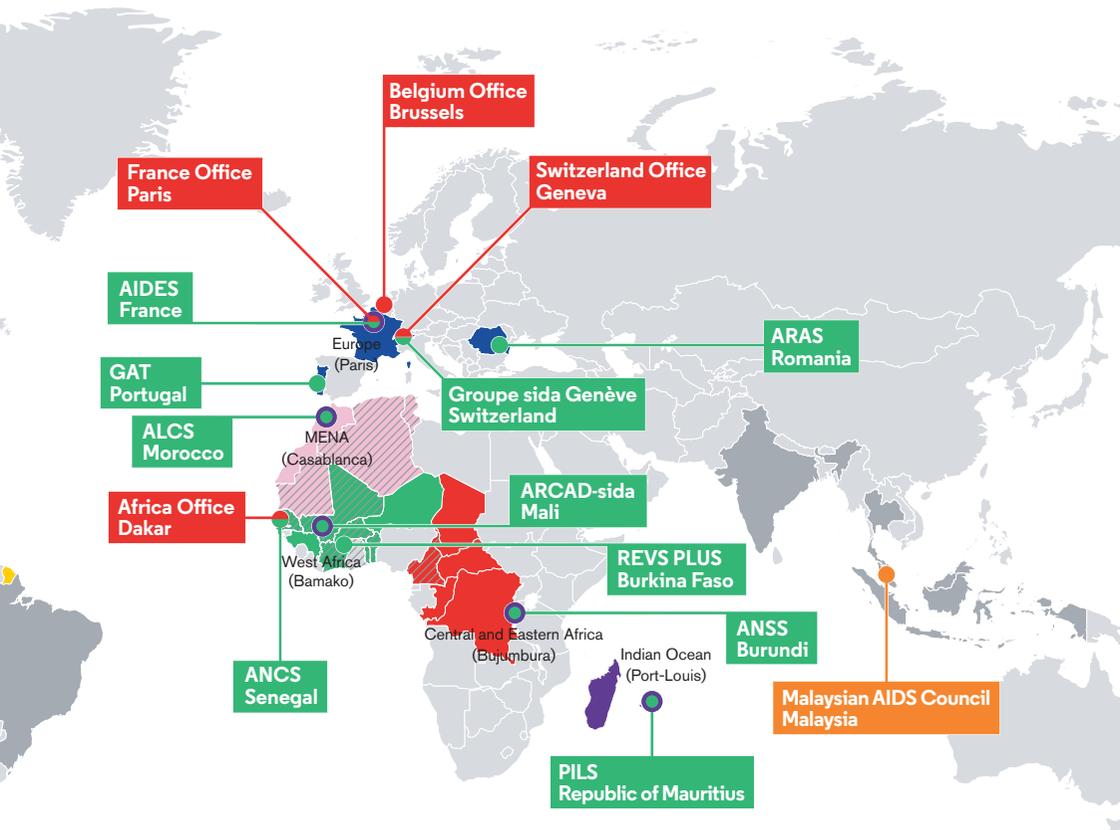
www.pils.mu

Coalition PLUS has three other members: ANCS in Senegal, REVS PLUS in Burkina-Faso, and ANSS in Burundi, all of whom conduct community-based research. At the time of the compilation of this brochure, the ANCS was not yet a member of Coalition PLUS, and results were not yet available regarding the research projects conducted by the ANSS and REVS PLUS. The ANSS is currently working on a project about the fate of people lost to follow-up, as well as an epidemiological study called IEDEA (International epidemiologic databases to evaluate AIDS). REVS PLUS is working specifically on a referencing-counter-referencing system between testing centres and medical care services to guarantee continuity of care.

→ Coalition PLUS

Coalition PLUS is an international network of community-based NGOs involved in the fight against HIV/AIDS and viral hepatitis. Founded in 2008, Coalition PLUS is active in almost 40 countries in conjunction with approximately 100 civil society organisations. According to the principle of shared governance, our coalition includes 13 member organisations, from the global North and South, in its strategic decision-making process. As a part of the community-based approach, Coalition PLUS advocates that individuals who are infected with, affected by, or particularly exposed to HIV and HCV are systematically involved in the process of decision-making, implementation and assessment of healthcare programmes that concern them. Through the various programmes conducted by its secretariat and its 6 sub-regional action platforms, Coalition PLUS seeks to strengthen the capacities of community-based organisations while creating privileged spaces for the sharing of knowledge and expertise. Committed to maintaining excellence in its management and the essential principle of democratic governance, Coalition PLUS has been named as a *Don en confiance*, or a “trusted donation”, by the organisation *Comité de la Charte*.





■ **HCV Project.**

▨ **Members of the Global Alliance of Communities for Health and Rights (AGCS PLUS).**

■ **Platform Europe** (France, Portugal, Romania, Switzerland).

■ **Platform MENA** (Algeria, Morocco, Mauritania, Tunisia).

■ **Platform West Africa** (Benin, Burkina Faso, Ivory Coast, Guinea Conakry, Mali, Niger, Senegal, Togo).

■ **Platform Central and Eastern Africa** (Burundi, Cameroon, Central African Republic, Republic of the Congo, Democratic Republic of the Congo, Rwanda, Chad).

■ **Platform Indian Ocean** (Union of the Comoros Islands, Madagascar, Republic of Mauritius, Mayotte, Reunion Island, Rodrigues, Seychelles).

■ **Platform Americas-Caribbean** (Ecuador, Bolivia, Quebec, French Guiana, Martinique, Guadeloupe, San Martin Island).



➔ Community-based research

Research by, for and with persons affected by HIV and-or viral hepatitis

Community-based research is above all research. It respects the same requirements for rigor and methodology as what is referred to as “traditional” scientific research, and it helps generate new knowledge, through scientific articles published in peer-review journals and presentations at scientific conferences. However, it is distinguished by its community-based approach.

Community-based research seeks to combine academic and scientific expertise with knowledge derived directly from the experience of persons *affected by* and *infected with* the AIDS virus and viral hepatitis.

It entails a collaboration at each stage of the research process with researchers from the worlds of academia and science, but also with HIV-positive individuals, people who are members of the most exposed groups, and even activists engaged in the fight against AIDS. In its close collaboration with teams that work in advocacy, prevention, and provision of care, community-based research also provides significant support for actions regarding prevention, information and the fight against discrimination waged each and every day by actors in the field.

Community-based research is scientific, ethical, and political. It provides greater visibility of the needs of people who are directly affected by HIV and viral hepatitis. Community-based research thereby contributes to social transformation. By bringing together countries from the global North and South in this common struggle, the community-based research conducted within Coalition PLUS has added an additional dimension: to jointly advance HIV and viral hepatitis research at the international level.



➔ The stages of a community-based research project



PrEP

PrEP (HIV pre-exposure prophylaxis) is a prevention strategy whereby an HIV-negative individual takes antiretroviral drugs to prevent HIV infection. It is part of a healthcare offer that can include regular testing and referrals for comprehensive medical care. Today, considered a fully-fledged prevention strategy, it reduces the number of new infections with a particular attention on the most exposed populations. Despite being recommended by the WHO for the populations most exposed to HIV, this tool is not available or difficult to access in most countries, especially in the global South. Consequently, Coalition PLUS member organisations deal with very diverse situations in terms of access to PrEP. To support its development, member organisations are conducting a number of field surveys to assess knowledge of this tool, its acceptability, the conditions for potential access, and its impact on HIV incidence.



➔ Flash ! PrEP in Europe

2016 – AIDES, ARAS, GAT, and Groupe sida Genève

Context

In January 2016, France authorised PrEP through an exceptional mechanism: a temporary recommendation for use. This was in part the result of intensive advocacy by AIDES for free and rapid access to PrEP, advocacy which was notably boosted by the results of the ANRS-Ipergay study¹ and of the “Flash! PrEP France” survey conducted in 2014. The marketing authorisation for the molecules used in PrEP in February 2017 allowed its recognition as a full-fledged prevention strategy that is fully reimbursed by the French health insurance system. Coordinated by the research departments at AIDES, Coalition PLUS and the Universities of Amsterdam and Maastricht, the “Flash! PrEP in Europe” survey replicated and enriched the French survey at the European level, in partnership with the Universidad Autonoma de Madrid and an ensemble of organisations fighting HIV in 12 countries in Europe.



Objectives

- Characterise HIV-negative individuals who know about, are interested in, and-or who have the intention to use PrEP;
- Evaluate the use of PrEP outside clinical trials or delivery structures, also known as “informal PrEP”.

Methodology

- 12 participating European organisations, 4 of which are members of the Coalition PLUS European platform: AIDES (France), ARAS (Romania), GAT (Portugal), and Groupe sida Genève (Switzerland);
- Diffusion of an online questionnaire (15 June-15 July 2016) by all partners in the participating countries and translated into 10 languages;
- Promotion of the survey among concerned populations by the partners in the various countries;
- Data collection regarding socio-demographic information, sexual practices and prevention methods, in addition to the knowledge about, interest in, and usage of PrEP.



Results

- 15,880 respondents, 92% of whom were men, and 70% of whom live in Germany;
- The level of knowledge of PrEP was strongly dependent on the respondents' profiles (from 37% of men living in Germany to 77% among men living in other countries);
- Interest in PrEP was relatively high (44% among respondents in Germany, 44% among transgender respondents, and 54% among men from other countries);
- Women expressed a lower level of interest in PrEP (18% of respondents), but the ones who were interested were often most exposed, or perceived themselves to be at high risk;
- 50% of MSM said they were interested in taking PrEP: MSM who reported behaviours that could increase their exposure to HIV, who were identified to be most exposed to infection, and who had a "high-rather high" self-perceived risk of contracting HIV were most often interested in PrEP;
- Transgender respondents declared behaviours that could increase their exposure to HIV, however, among them, transgender women were most exposed to infection and more often interested in PrEP;
- The majority of respondents thought that PrEP should be: dispensed at community health centres (42.0%) or at a general practitioner's (58.4%), prescribed as part of an overall prevention strategy (81.3%), free or subsidised by the national healthcare service (83.7%);
- A non-negligible number (~2%) of respondents were already taking PrEP on an informal basis, often without appropriate medical supervision.

The participating organisations used the results in their national advocacy work, especially within their social networks, during discussions at internal meetings and with their beneficiaries, discussions with the Ministry of Health (in Portugal), and in training and national campaigns (World AIDS Day). At the European level, the results were used to stimulate a dialogue regarding PrEP as part of the initiative "PrEP in Europe". The questionnaire was also used in a survey conducted with MSM in Kazakhstan and a national survey in Cyprus.

Scientific contributions

Delabre R. *et al.* (October 2018). *HIV-related Risks and Interest in Pre-exposure Prophylaxis (PrEP) among Transgender Respondents of the Community-based Survey 'Flash! PrEP in Europe'*. Oral presentation at HIV Research For Prevention, Madrid, Spain.

Delabre, R. *et al.* (November 2017). *'Yes, I'm interested in taking PrEP': factors associated with PrEP interest among women in Europe – Results from the community-based survey 'Flash! PrEP in Europe'*. Oral presentation at AIDS Impact, Capetown, South Africa.

Bernier, A. *et al.* (July 2017). *Barriers to uptake of pre-exposure prophylaxis among respondents to the 'Flash! PrEP in Europe' survey*. Oral presentation at AIDS 2017, Paris, France.

¹ *Intervention préventive de l'exposition aux risques avec et pour les gays, or Preventive intervention against exposure to risks with and for gay people.*



➔ Survey on the acceptability and intention to use PrEP in Ecuador

2016 – Kimirina

Context

In Ecuador, UNAIDS estimates the number of PLHIV at 36,000 and the number of new infections per year at 2,000. Transgender women and MSM are among the groups most affected by HIV, with a respective prevalence of 35% and 16%¹. Just as treatment is helping to save millions of lives, combination prevention, including PrEP, can help stop new HIV infections. Following the international study “iPrEx” (2007-2011) on the efficacy of PrEP, in which Ecuador participated, the organisation Kimirina, a Coalition PLUS member, and the Ministry of Public Health decided to conduct a survey on the acceptability and intention to use PrEP in Ecuador.



Objectives

- Determine the level of acceptability of PrEP among potential users (MSM and transgender women) and healthcare professionals who could dispense PrEP;
- Characterise and evaluate the proportion of MSM and transgender women interested in using PrEP, as well as the proportion of informal PrEP users.

Methodology

- Quantitative survey of MSM and transgender women in Quito and Guayaquil. Kimirina used the “Flash! PrEP France” survey (2014) as a base for the development of this survey;
- Qualitative study among MSM and transgender women via focus groups (4 with HIV-negative MSM, 4 with HIV-negative transgender women, and 4 with healthcare professionals), and 13 in-depth interviews with authority representatives.

Results

- 379 MSM and 335 transgender women participated in the survey;
- 10% of MSM knew about PrEP before the survey (33% via social media networks-internet and 28% via NGOs or the community) and 10% of transgender women knew about PrEP before the survey (22% via social media networks-internet and 44% via NGOs and the community);
- 16% of transgender women and 5% of MSM had already used PrEP;
- 91% of MSM and 93% of transgender women said that they were interested in PrEP. 88% of MSM and 82% of transgender women said they would prefer taking a daily dose;
- The majority of respondents believed that public healthcare agencies should be responsible for dispensing PrEP and providing medical follow-up.

The project has led to lobbying the Ministry of Public Health to implement PrEP programmes across the country. To bolster this effort, Kimirina will conduct a new study in 2019 focusing on the feasibility of PrEP within the community of transgender women at its community-based centre in Quito, in collaboration with the Ministry of Health and with financing from the city hall of Paris.

Scientific contribution

Acosta, M. *et al.* (July 2018). *Knowledge and Intention to use PrEP among the Male-to-Female population in Ecuador: Results from a community-based survey.* Poster presented at AIDS 2018, Amsterdam, The Netherlands.

¹ UNAIDS data, 2017.



➔ PrEPare_Morocco – PrEP acceptability pilot study among the populations most exposed to HIV in Morocco

2017-2018 – ALCS

Context

Morocco is facing an HIV/AIDS epidemic among certain populations, with a prevalence of 1.3% among sex workers (SW), 5.7% among MSM, and 7.9% among intravenous drug users (IDU)¹. PrEP is an effective strategy for significantly reducing new infections among these populations. To support advocacy for increased access to this new prevention tool, ALCS, a Coalition PLUS member in Morocco, led a study on the acceptability and feasibility of PrEP among the most exposed populations, in collaboration with the Moroccan Ministry of Health, UNAIDS, and the Global Fund to Fight AIDS, Tuberculosis, and Malaria.



Objectives

- Assess the degree of acceptability of taking PrEP by MSM and SW in Morocco and determine the percentage of these two populations that takes PrEP following the daily regimen;
- Determine the socio-demographic characteristics, knowledge of PrEP, and potentially risky behaviour of MSM and SW interested in taking PrEP and those who take it following the daily regimen.

Methodology

- Recruitment and PrEP dispensation following the daily regimen for 400 participants (300 MSM and 100 SW);
- Study conducted in 3 cities: Casablanca, Marrakech, and Agadir;
- 7 trained physicians and 12 peer educator coordinators trained in PrEP to ensure a monthly follow-up with participants over a 9-month period (physical examination, blood test, discussions regarding treatment tolerance, timing, and potentially risky behaviours during the previous week);
- Semi-structured interviews with survey participants and potential beneficiaries who refused to participate in the study.



Results

- Out of the 302 MSM who were recruited, 279 were eligible, 240 received a first box of PrEP, and 170 (61%) were present for their first medical follow-up visit;
- All of the 97 SW who were recruited were eligible; 82 received a first box of PrEP, and 37 (38%) were present for their first medical follow-up visit;
- MSM and SW who participated in the interviews were generally well informed about PrEP;
- The launch of this study highlighted specific obstacles to PrEP implementation, including the need for more communication on this preventive strategy, the lack of stock, and the high level of mobility of participants.

Following an assessment by the Global Fund, ALCS obtained an extension and an increase of PrEP access in July 2018 for 1,000 SW and MSM until 2020 in 4 cities in Morocco. ALCS shared its experiences with partners in the region, who in turn began to advocate for the acceptance of PrEP as a prevention tool. Capacity-building workshops on implementing PrEP among the most exposed populations have also been planned for Coalition PLUS Middle East and North Africa (MENA) Platform.

Scientific contribution

Ben Moussa, A. *et al.* (April 2018). *PrEPare Morocco : Expérience pilote d'acceptabilité de la PrEP par les populations clés au Maroc : résultats préliminaires*. Oral presentation at the 9th International Francophone Conference on HIV and Hepatitis (AFRAVIH 2018), Bordeaux, France.

¹ UNAIDS data, respectively from 2016, 2015, and 2015.



➔ Survey: is PrEP use in French-speaking Switzerland underestimated?

2018 – Groupe sida Genève

Context

In Switzerland, in the absence of a solid recommendation by the public health authorities, PrEP is not covered by the private healthcare insurance system and remains expensive. However, PrEP uptake is steadily increasing. Community health centres and certain physicians are writing out prescriptions that are frequently used to obtain PrEP from pharmacies abroad or online. In 2017, a survey conducted by the Institute of Social and Preventive Medicine of Lausanne (IUMSP) among prescribing physicians found that 119 new prescriptions and 83 renewed prescriptions had been written in the previous year. To update the data on the use and number of PrEP users, Groupe sida Genève conducted a brief survey on the use of PrEP in French-speaking Switzerland. This survey was carried out in partnership with Checkpoint Vaud and Checkpoint Genève.



Objectives

- Determine how many people have used PrEP in French-speaking Switzerland;
- Determine how many of them buy PrEP abroad.

Methodology

- Distribution of an anonymous online questionnaire to 110 prescribers in private practice, at Checkpoints, sexual health clinics for men, and hospitals in the cantons of Geneva and Vaud;
- The questionnaire collected information regarding the number of new prescriptions of PrEP, the number of renewed prescriptions of PrEP, and the number of patients who had purchased generic PrEP in the last three months.



Results

- 36 prescribers in total responded to the survey (33%);
- 20 respondents had written new prescriptions for PrEP (106 new prescriptions) and/or renewed prescriptions for PrEP (143 renewals) in the last 3 months (January-March 2018);
- 66% of patients said they had bought their generic medication abroad;
- The results point to a strong increase in the use of PrEP in French-speaking Switzerland since the 2017 survey;
- Purchases of generic PrEP abroad suggest that that users of PrEP consider its price in Switzerland as a barrier;
- The increase in the use of PrEP appears due to a demand among users and community-based clinics, as opposed to a public health policy decision;
- The survey emphasised the importance of a solid public health recommendation for PrEP and the need for its reimbursement by private health insurance schemes to support the increased adoption of PrEP by users and to encourage the manufacturers of generics to sell their molecules in Switzerland before the expiration of the SPC¹ for TDF/FTC².

¹ The Supplementary Protection Certificate is a special certificate that extends the rights and obligations of an owner of a pharmaceutical patent in European Union countries.

² TDF/FTC: Tenofovir disoproxil fumarate + emtricitabine: an association of molecules used to make PrEP.



➔ ANRS Prévenir – HIV prevention in Île-de-France

2017-2020 (ongoing) – AIDES

Context

With a large population of MSM and migrants from high prevalence areas, the Ile-de-France region had 42% of all new cases of HIV in France in 2015¹.

Since its authorisation in France in 2016, PrEP has created new possibilities for preventing HIV, especially in the context of a concentrated epidemic among certain populations. To assess the impact of this new strategy for preventing the HIV/AIDS epidemic in Ile-de-France, AIDES and Coalition PLUS have conducted the “ANRS Prévenir” study since 2017, in collaboration with the Public Hospitals of Paris (AP-HP) and with financing from the French National Agency for AIDS and Viral Hepatitis Research (ANRS).



Objectives

- Contribute to the reduction in the number of new HIV infections in the Ile-de-France region by increasing access to PrEP for non-infected individuals with high exposure to HIV in order to accelerate the uptake of PrEP among this population;
- Document, during the third year of the study, a reduction in the number of new diagnoses of HIV infections among this population.

Methodology

- A prospective cohort study on the implementation of a PrEP-based prevention strategy among individuals highly exposed to HIV in the Ile-de-France region;
- Recruitment of 3,000 participants, mainly MSM and transgender individuals (85%), as well as heterosexual men and women, migrants, and other persons exposed to HIV (15%);
- 3-year cohort study, with 2 years for recruitment and one additional year after the end of recruitment to assess the project's epidemiological impact in the Ile-de-France region;
- Participants are monitored during the first and third months, and once every 3 months thereafter;
- Conducted at twenty infectious disease departments and CEGIDDs² in the Ile-de-France region.



First results

- Between May 2017 and May 2018, 1,435 HIV-negative volunteers with high exposure to HIV were recruited (2,000 people were included by October 2018);
- Among them, 44% take PrEP daily and 53% use it on demand, depending on their sexual activity;
- No case of HIV infection occurred among the volunteers, neither among those taking PrEP continuously, nor among those who opted for the on-demand regimen;
- The study was not halted for adverse events related to the treatment.

Scientific contribution

Molina J-M, Ghosn J, Beniguel L, Rojas-Castro D *et al.* (July 2018). *Incidence of HIV-infection in the ANRS Prevenir study in Paris region with daily or on-demand PrEP with TDF/FTC*. Oral presentation at AIDS 2018, Amsterdam, The Netherlands.

¹ Lot F. Point Epidemiological update – HIV/AIDS Infection and STI – November 23, 2015. *Institut de Veille Sanitaire*, 2015.

² CEGIDD, the *Centre Gratuit d'Information, de Dépistage et de Diagnostic*, or the Free Center for Information, Testing and Diagnosis of infections by the human immunodeficiency virus (HIV), viral hepatitis, and sexually transmitted infections (STI).



Testir

ng

To reach the objective of 90% of PLHIV know their serological status between now and 2020, it is essential that community-based testing develops alongside “traditional” medical testing. Training volunteers and peer educators enables direct contact with individuals most exposed to HIV to provide rapid testing, to raise awareness about the importance of treatment, medical follow-up, and prevention of transmission. Studies on testing can have multiple objectives: to understand the reasons that lead various populations to get tested or not, in order to implement new, more adapted testing strategies, or to support lobbying efforts for the legalisation of community-based testing by community actors.



➔ Pilot study for the creation of a community-based HIV testing programme in Quito, Ecuador

2015-2016 – Kimirina

Context

In Ecuador, access to HIV counselling and voluntary testing services is difficult for the most exposed populations, due to geographic, economic, and cultural obstacles. Mistrust of the healthcare system, the fear of a lack of confidentiality, and the fear of stigmatisation are often barriers to HIV testing. The implementation of a rapid HIV testing service in primary healthcare and community-based facilities is a recommended practice for improving testing among the most exposed populations to reduce HIV infection diagnoses at a late stage. It is for this reason Kimirina implemented a community-based HIV testing programme within the context of a pilot study and in partnership with the public healthcare system of Quito.



Objectives

- Determine the feasibility and acceptability of implementing a community-based HIV testing programme for the most exposed populations (MSM and transgender individuals) in the city of Quito;
- Estimate HIV prevalence and incidence rates among the target populations;
- Determine facilitating factors and obstacles to implementing such a programme.

Methodology

- Training of a multidisciplinary team (counsellors, physicians, nurses, paramedics, community-based agents, and activists);
- Implementation of rapid HIV testing through:
 - The opening of two community-based testing centres in January 2016, located in the centre and the southern portion of the city of Quito;
 - A mobile community-based team present in areas highly frequented by the populations most exposed to HIV (in discotheques, bars, saunas, the street, parks, etc.);
- Data collection (socio-demographic, behavioural, and HIV testing).



Results

- Among the 285 people contacted, 168 accepted to be tested (62% of them were MSM, 30% were transgender and 8% were women);
- 41% (n=69) of participants were tested for HIV for the first time;
- 10% (n=17) of participants tested positive, 6 of whom were MSM (6% of MSM), and 11 of whom were transgender (22% of transgender individuals);
- 88% (n=15) of the participants who tested HIV-positive already knew of their status.

The results of this pilot project led to the generalisation of community-based testing in Quito and Guayaquil. This expanded offer has enabled the testing of 18,000 individuals in one year.



“Because of the positive results of the pilot project conducted by Kimirina and the City of Quito in 2016, the national authorities authorised community-based testing in other areas of Quito and Guayaquil. The project was also expanded in 2018 to 5 other cities in the country with high HIV prevalence rates.”

Lupe Orozco Ramos – Community-based researcher – Kimirina



HERMETIC – HIV European Research on Mathematical Modelling & Experimentation of HIV Testing in Hidden Communities

2015-2018 – AIDES (for France)

Context

In the last few years, better access to antiretroviral treatments has helped considerably lower HIV/AIDS morbidity and mortality rates. However, the average time between HIV infection and an HIV-positive diagnosis in Europe is three years¹. In all, it is estimated that 15% (n=120,000) of PLHIV do not know their serological status in this geographic zone². This "hidden epidemic" feeds the dynamics of the disease and complicates the fight against new HIV infections. The HERMETIC project aimed to respond to the problems of the absence or late diagnosis of HIV infection. It specifically tried to better understand the HIV epidemic, in order to improve targeting of the areas and groups that should be tested on a priority basis, using innovative actions. This study was coordinated by INSERM and conducted in partnership with several organisations engaged in the fight against AIDS in Europe: the Institute of Tropical Medicine and the Scientific Institute of Public Health in Belgium, the University of Riga in Lithuania, and AIDES in France.



Objectives

- Determine the number of undiagnosed HIV infection cases and the incidence of HIV in France, Belgium, Estonia, and Lithuania;
- Determine the probable delay between the time of HIV infection and diagnosis;
- Develop and implement innovative HIV testing initiatives for undiagnosed individuals;
- Evaluate these HIV testing initiatives and develop a guide to translate the mathematical model results into interventions.

Methodology – France

- Mathematical modelling using HIV surveillance data to identify hidden populations in each participating country. In France, this concerned migrants born in sub-Saharan Africa (MSM or heterosexuals) and living in the Seine-Saint-Denis department;
- Implementation of innovative actions for the identified populations. In France, two actions were implemented: 1. HIV testing at home through door-to-door prevention actions targeting people born in sub-Saharan Africa; 2. HIV testing for everyone, available and visible in a mobile unit parked in the neighbourhood;
- Conducted in 3 urban areas in Seine-Saint-Denis (the Francs-Moisins housing project in Saint-Denis, the Beaudottes housing project in Sevran, and La capsulerie in Bagnolet), between October 2016 and February 2017;
- Collection of socio-demographic and behavioural data during the study period among the targeted populations.



Results – France

- 290 migrants born in sub-Saharan Africa (143 men and 147 women) were encountered during the door-to-door actions;
- 142 migrants born in sub-Saharan Africa were tested in the mobile unit, and 43 more were tested at home;
- 39% of men and 33% of women were interested in being tested;
- The people who were not interested in being tested (64%) claimed mainly that “they didn’t think they were affected” and that they “had already been tested”;
- A high level of mobilisation to participate in this innovative community-based project, for which the visibility phase was well conducted and accepted by local AIDES community-based agents.

The new “go towards” approach revealed a real interest in home testing among the local population, which was well received. It also improved cooperation with key figures in the neighbourhood for the promotion of the initiative among young people, the facilitation of a dialogue with residents, and the acceptance of AIDES agents as healthcare actors.



“The originality of the HERMETIC project’s door-to-door strategy put global health problems on the agenda for discussion in the households of those we encountered. This was also an opportunity for them to consider or take a rapid HIV test, which was often their first time being tested! I think this strategy was relevant, because it allowed people who are the farthest from the healthcare system, given their migrant status, to understand and accept HIV testing and prevention.”

Armand Totouom – AIDES employee

Scientific contributions

Sondey, J. *et al.* (July 2017). *Acceptability of door-to door rapid HIV testing among sub-Saharan African men and women living in the Paris region*. Poster presented at IAS 2017, Paris, France.

Sondey, J. *et al.* (October 2017). *Acceptabilité du dépistage à domicile pour les hommes et les femmes nés-es en Afrique subsaharienne résidant en Seine Saint-Denis dans le cadre du projet HERMETIC*. Poster presented at SFLS 2017, Nice, France.

¹ Ard van Sighem *et al.*, and the ECDC HIV/AIDS Surveillance and Dublin Declaration Monitoring Networks (2017, Nov), *Reduction in undiagnosed HIV infection in the European Union/European Economic Area, 2012 to 2016*.

² Pharris A *et al.*, ECDC HIV/AIDS Surveillance and Dublin Declaration Monitoring Networks (2016, Dec), *Estimating HIV incidence and number of undiagnosed individuals living with HIV in the European Union/European Economic Area, 2015*.

➔ KACRAI-HIV – Detection of HIV primo-infection in Portugal: 4th generation rapid test or an HIV-RNA molecular test instead of intervention?

2016-2019 (en cours) – GAT

Context

Unlike the 3rd generation¹ rapid tests, the 4th generation HIV rapid tests are able to detect, in addition to antibodies, the presence of the p24 antigen present during the primary infection phase (or acute infection, most often asymptomatic). The 4th generation tests² thus enable the detection of seroconversions at 2 weeks of infection (compared to 1 month with the 3rd generation tests). This is important because the viral load is very high in the primary infection phase, favouring transmission. Earlier detection with the 4th generation tests thereby reduces time to treatment initiation, limiting the impact on the individual's immune system and the risk of transmission. To assess the efficacy of the 4th generation test in the context of an HIV rapid test programme, the organisation GAT, Coalition PLUS member in Portugal, led a study co-financed by the pharmaceutical laboratory Abbott.



Objectives

- Assess the efficacy of the 4th generation test in detecting HIV primary infections as part of an HIV rapid testing programme at a community-based counselling and testing centre for MSM in Lisbon (CheckpointLX);
- Develop and implement a system to better identify MSM with primary infection so that they can receive immediate treatment.

Methodology

- Between November 2016 and November 2017, utilisation of 4th generation tests for MSM who came for HIV testing at CheckpointLX;
- HIV-RNA molecular test³ for MSM with a positive 4th generation test result, for MSM presenting with primary infection symptoms, and for MSM whose sexual partner was diagnosed as HIV-positive at CheckpointLX within the last 6 months.



Results

- 2,890 4th generation tests were performed, 88 of which were positive: 1 for the p24 antigen (but which was confirmed as negative), 1 for the antigen and the antibody, and 86 for the antibody (4 of which were confirmed as negative);
- 115 HIV-RNA were performed, 27 of which were negative (1 confirmed positive) and 88 of which were positive: 1 for the p24 antigen (confirmed as negative), 1 for the antigen and the antibody (confirmed as positive and as an acute infection), et 86 for the antibody (9 refused confirmation, 4 were confirmed negative, and 73 were confirmed positive, 26 of which as recent infections);
- The HIV-RNA molecular test detected a seroconversion for a MSM whose sexual partner was diagnosed in the last 6 months, while his 4th generation test was negative;
- The 4th generation tests did not add value to the detection of infections through the p24 antigen in the absence of antibodies. The targeted molecular HIV-RNA test and the on-site confirmation avoided anxiety and useless meetings while reducing the confirmation timeframe from 6 weeks to 1 hour.

Following this study, GAT decided not to give priority to 4th generation tests at Checkpoint-LX, as this strategy is more costly and, for the time being, not more effective than the HIV-RNA molecular tests that are already being offered.

Scientific contributions

Carvalho Rocha, L.M. *et al.* (October 2018). *Acute HIV infection detection: rapid fourth-generation test or rapid molecular point-of-care HIV test?* Poster presented at HIV Glasgow 2018, Glasgow, United Kingdom.

Carvalho Rocha, L.M. *et al.* (July 2017). *Men who have sex with men primary HIV detection at CheckpointLX, Lisbon, Portugal.* Poster presented at IAS 2017, Paris, France.

¹ A 3rd generation test only detects antibodies. It detects HIV infection among 50% of people on the 22nd day, and among 99% of people at the end of the 3rd month of infection.

² A 4th generation test detects antibodies and the p24 antigen. It detects HIV infection among 50% of people on the 18th day, and among 99% of people after one and a half months of infection.

³ A test that detects the virus' RNA and primo-infections.

**The right
to health
for drug
users**

The image features a solid pink background. At the bottom, there is a decorative pattern of small, scattered red dots that gradually increases in density towards the bottom edge. The text is centered and rendered in a bold, white, sans-serif font.

care

Users of psychoactive products via injection are among the populations most exposed to HIV and HCV, given the transmission of these viruses through blood exposure. To help drug users (DU) reduce their risk, the member organisations of Coalition PLUS offer specific support and solutions adapted to their practices. In the face of repressive policies in some countries and the lack of adequate risk reduction measures (needle exchange programmes, substitution therapies, etc.), Coalition PLUS advocates at the regional, national, and international levels for drug policy reform to take into account the fundamental rights of DU.



Seroprevalence and potentially risky behaviours regarding HIV and hepatitis B and C infections among drug users in Mali

2014-2015 – ARCAD-SIDA

Context

In Mali, HIV prevalence rates have been estimated at 24.2%¹ among sex workers and at 13.7% among MSM². However, there is no estimate for drug users, who are nevertheless disproportionately affected by HIV and the hepatitis B and C viruses. To curb these epidemics within this population and to meet the needs of drug users (DU), ARCAD-SIDA, a Coalition PLUS member in Mali, assessed the prevalence of HIV, HCV and HBV infections, as well as potentially risky behaviours, among DU in Bamako, with the support of Expertise France.



Objectives

- Estimate the seroprevalence of HIV, HCV and HBV among users of heroin and crack cocaine in Bamako;
- Define the socio-demographic profile and consumption of DU in Bamako;
- Identify the healthcare needs of DU, especially in terms of HIV and viral hepatitis prevention and treatment;
- Assess the primary potentially risky behaviours of transmission;
- Evaluate the access to testing and medical care.

Methodology

- Preliminary mapping of drug consumption in Bamako and a situational analysis to adapt the survey's methodology in October 2014;
- 500 persons selected using a sampling method driven by the respondents (RDS – Respondent Driven Sampling);
- A biological and behavioural study using face-to-face questionnaires on the socio-demographic characteristics of participants, their history of drug consumption, their potentially risky behaviours, and their knowledge of communicable illnesses and the healthcare system;
- Blood sample collection for HIV, HCV and HBV tests;
- Qualitative survey (interviews, focus groups, observations) to explore certain issues in greater depth among sub-groups of interest that are barely or not at all represented in the quantitative survey, such as intravenous drug users (IDU), women, and young DU, in order to determine drug use practices, barriers to accessing treatment and healthcare services, or furthermore, risk and risk reduction.



Results

- HIV prevalence among users in Bamako is 2% (compared to 1.6% among Bamako's general population); it is 5% among IDU;
- Prevalence is high among sub-populations characterised by vulnerability factors: sex workers (20%) and users who have been incarcerated (3%);
- The prevalence of viral hepatitis is 3% for HCV and 15% for HBV;
- Injection use concerns a small proportion, with 8% of people having injected at some point in their lives and 5% actively injecting;
- 35% of IDU reused their syringes and 26% shared their syringes;
- 13% of IDU (57 men and 6 women) offered sexual favours for money or in-kind payments (such as drugs);
- HIV knowledge was average (30% had in-depth knowledge) and viral hepatitis knowledge was low (less than half of IDU had heard of HCV);
- HIV testing was quite low (less than half had already been tested) and was not routine (only 20% of users had been tested in the last 12 months). As a result, 90% of HIV-positive DU were unaware of their serological status.

The study data was used by the ARCAD-SIDA advocacy team during meetings with political decision-makers and in awareness-raising workshops with law enforcement agents to reduce repression. The study resulted in the incorporation of DU as a key population in the draft law on HIV in Mali, as part of the 2013-2017 National Strategic Framework in the fight against AIDS. The results were also used in the country's Global Fund 2016-2017 concept note for the creation of an action programme to reduce HIV risk among DU in Bamako. ARCAD-SIDA became a sub-recipient of Plan International Mali for the implementation of the prevention programme among IDU in Bamako.

Scientific contribution

ARCAD-SIDA's participation in the symposium "Risk reduction and 'the war on drugs': community work in hostile environments in French-speaking Africa and the Caribbean" as part of the AIDS2018 conference.

¹ ISBS study, 2009.

² UNAIDS, 2015.



→ preBupIV – A quantitative-preliminary survey to assess the use of intravenous buprenorphine in France

2015 – AIDES

Context

Despite easy access to oral forms of opioid substitution treatments (buprenorphine and methadone) in France, some DU continue to inject substitutes, essentially dissolved buprenorphine tablets. This practice can lead to health risks such as cutaneous complications (abscesses, cellulite, etc.) or the transmission of HIV and-or HCV in the case of needle sharing. A regulated prescription for an injectable treatment for opioid dependency could limit these risks and integrate these individuals into the healthcare system.

In 2014, MILDECA¹ commissioned a study to assess if an injectable substitution treatment was relevant for DU for whom existing substitution treatments were not working. Hence AIDES — in partnership with INSERM (SESSTIM) — designed a preliminary survey to better understand the profile of IDU eligible for intravenous (IV) buprenorphine and their willingness to receive it.

Objectives

- Identify the profiles of buprenorphine and opioid injectors who go to risk-reduction centres for DU (CAARUD) and to healthcare centres that are specialised in addiction support and prevention (CSAPA);
- Describe opioid use (injected dose, frequency of injection, injection practices);
- Identify the needs of IDU in terms of injectable opioid substitution treatments ;
- Evaluate the acceptability of an opioid dependency treatment using injectable buprenorphine among IDU.

Methodology

- Cross-sectional, community-based research survey conducted in metropolitan France in close collaboration with research teams and users of CAARUD and CSAPA. Questionnaires were completed face-to-face and online (on psychoactif.org);
- Analysis of the factors associated with the acceptability of an injectable buprenorphine treatment among eligible individuals. Among those who were ready to use the treatment, an analysis was carried out to identify their characteristics and acceptance of a therapy based on injectable buprenorphine with daily medical follow-up.



Results

- 557 respondents in all. Out of the 353 respondents eligible for the study, 59% had mainly injected buprenorphine, 16% morphine sulfate (known by the trade name Skenan), 15% heroin, and 10%, other opiates;
- In total, 83% of the respondents were in favour of an injectable buprenorphine treatment;
- The acceptability of IV buprenorphine was particularly high among opiate injectors who had experienced numerous injection-related complications. Acceptability was lower among those who inject morphine sulfate;
- Young injectors and those with a “stable” residence were less favourable to IV buprenorphine if daily medical supervision was required.

This community-based survey resulted in the identification of the necessary conditions for the introduction of the first injectable treatment for opioid dependence in France.

Scientific contributions

Roux *et al.* (2017). *Willingness to receive intravenous buprenorphine treatment in opioid-dependent people refractory to oral opioid maintenance treatment: results from a community-based survey in France*. Substance Abuse Treatment, Prevention and Policy, 12(1). DOI: 10.1186/s13011-017-0131-4.

Briand-Madrid *et al.* (2018). *Factors associated with perceived loss of libido in people who inject opioids: results from a community-based survey in France*. Drug and alcohol Dependence, 190:121-127. DOI: 10.1016/j.drugalcdep.2018.05.030.

A guide called “Le Mag PrébupIV” was produced, containing the results of the preliminary survey on the assessment of intravenous buprenorphine. It is available on the AIDES website: aides.org/actualite/drogues-vers-des-traitements-de-substitution-plus-adaptes.

¹ The French Inter-Ministerial Mission for the Fight Against Drugs and Addictive Behaviors.



➔ Qualitative study on young drug users' access to medical, psychological, and social services in Romania

2015 – ARAS

Context

In Romania, the population that consumes the most psychoactive drugs is aged 15-24 years¹. Several studies, carried out at the initiative and with the financial support of UNICEF (2010-2011), have described the issues related to drug use by adolescents and their consequences. As new psychoactive substances enter the market, limited access to risk reduction services for young DU poses a real public health problem. It is thus important to remove legal barriers to specific services (needle exchanges, substitution treatments, sexual and reproductive health, access to healthcare services) to children and young people.

In line with these projects, ARAS, a Coalition PLUS member, conducted a study on young IDU's access to medical psychological and social services. This study was financial supported by UNICEF and was a part of the project "Methodology for working with young drug addicts – an emergency".

Objectives

- Describe the effects of drug use on adolescents and their family environment;
- Determine the factors that condition adolescent IDU's access to specific assistance services related to their consumption of psychoactive substances;
- Describe the practices of prevention and assistance services for adolescent IDU in Bucharest and in four regions in Romania (Bacău, Cluj, Constanța, Iași).

Methodology

- Documentary analysis of the existing legal framework regarding access to services for adolescents;
- 10 individual interviews with young adult IDU who have been using drugs since adolescence (the interviews concentrated on drug use during adolescence), and one interview with the parent of an adolescent IDU;
- 27 individual interviews and 9 focus groups with physicians, psychologists, social workers and school counsellors.



Results

- Romanian law allows adolescent IDU to access all existing legal services for adult IDU with the consent of their parents or of a legal representative, in observance of the child's freedom of choice and decision;
- The study highlighted increasingly younger adolescents, dysfunctional family environments, mental health problems, problems of integration and poor academic performance;
- Adolescents' main barriers to accessing support services were the insufficient promotion of existing services, their parents' refusal, and the stigmatisation of adolescent IDU and their families, especially within the educational system;
- The legislation concerning adolescent IDUs must allow for an institutional collaboration between educational entities, emergency and primary healthcare facilities, social and child protection services, and the families.

The data from the study was used as supporting material in meetings with public authorities to call attention to the poignant gap between the law and reality when young DUs want to access health services. A practical guide was published on the methodology of working with DUs aged 10-18 years in order to inform professional health care workers for young IDUs.

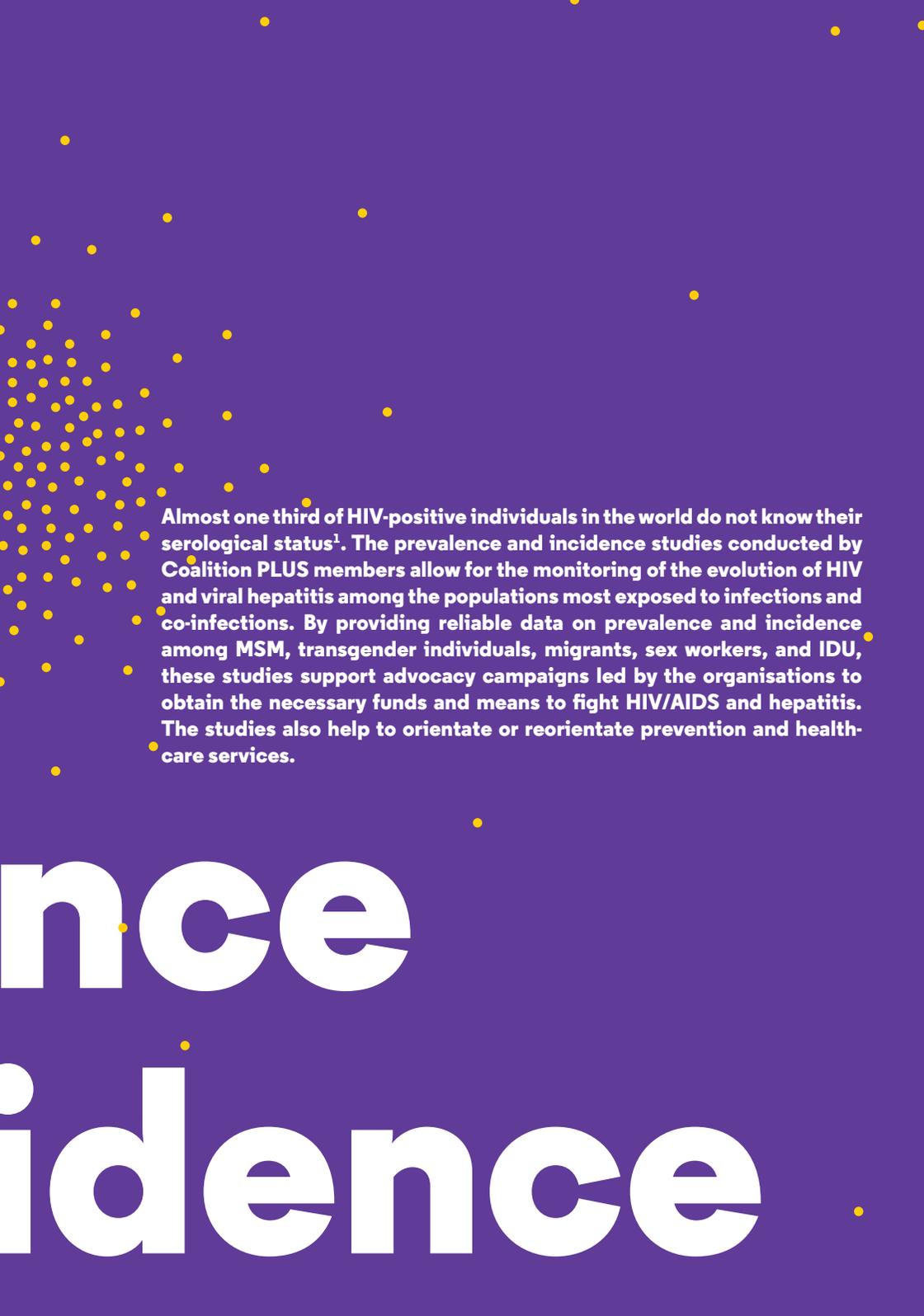
Scientific contribution

Creation of a UNICEF Manual, Methodology of working with at-risk adolescents and drug users (Metodologia de lucru cu adolescenții la risc și consumatori de droguri), ISBN 978-973-139-390-2.

¹ Data from the Romanian national anti-drug agency.



**Prevalence
and incidence**



Almost one third of HIV-positive individuals in the world do not know their serological status¹. The prevalence and incidence studies conducted by Coalition PLUS members allow for the monitoring of the evolution of HIV and viral hepatitis among the populations most exposed to infections and co-infections. By providing reliable data on prevalence and incidence among MSM, transgender individuals, migrants, sex workers, and IDU, these studies support advocacy campaigns led by the organisations to obtain the necessary funds and means to fight HIV/AIDS and hepatitis. The studies also help to orientate or reorientate prevention and health-care services.

nce

idence

➔ Rede de Rastreio Comunitária – community- based screening for HIV, viral hepatitis, and sexually transmitted infections in Portugal

2015-2019 (ongoing) – GAT

Context

In Portugal, 1,030 people were newly diagnosed as HIV positive in 2016¹, of whom 56% were at a late stage². MSM represented half of the HIV infections diagnosed among men, while people born outside Portugal represented more than one third of new HIV diagnoses (three quarters of them were from countries in sub-Saharan Africa)³. The HIV epidemic is thus highly concentrated among certain segments of the population, partly because of barriers to testing and healthcare services. Since 2015, the Portuguese community-based screening network, at the initiative of GAT and ISPUP⁴, the São João Hospital in Porto, and the AIDS Healthcare Foundation have therefore offered decentralised, immediate access to HIV, hepatitis, and other STI testing for the most exposed populations (MSM, sex workers, migrants, and IDU). This service provides an opportunity to carry out targeted prevalence and incidence studies.



Objectives

- Create additional, decentralised access to HIV, Hepatitis B and C, and syphilis testing;
- Collect prevalence and incidence data, and develop follow-up systems in partnership with organisations working with the most exposed populations;
- Know the socio-demographic characteristics of tested individuals, as well as their sexual behaviours and practices, their HIV, hepatitis and syphilis knowledge, as well as the use of prevention methods;
- Promote early diagnosis and effective monitoring throughout the entire process, together with the Portuguese national healthcare service;
- Provide prevention counselling to individuals with a negative test result to reduce the risks of infection.

Methodology

- The mobilisation of 27 community-based testing centres managed by 18 NGOs that offer testing;
- The training of 90 community workers in the prevention and testing of HIV, viral hepatitis, and syphilis;
- Tested individuals completed an anonymous questionnaire, collecting the following information: socio-demographic data, the results of the HIV, HCV and HBV, and syphilis tests, history of exposure to risk factors, sexual practices, experiences of violence, as well as awareness and use of different prevention methods.

Results

- Between January 2016 and December 2017, more than 90,000 rapid HIV tests were done; 2,126 tests were HIV-positive;
- Prevalence varied from 1% among tested women to 2% among men, and up to 11% among transgender individuals;
- 43% of the tested individuals had never taken an HIV test before and more than 75% had never been tested for viral hepatitis and syphilis;
- 18% of the tested individuals did not systematically use condoms with their casual partners.

This community-based screening network has provided essential data at the national level, which was taken up by the WHO in its guide to best practices. Since its creation, all the member organisations of the network have offered HIV, HCV, HBV and syphilis testing.

Scientific contributions

Simões, D. *et al.* (November 2017). *Community Based Screening Network: linking science, practice and community for early diagnosis*. Poster presented at the World Hepatitis Summit 2017, São Paulo, Brazil.

Simões, D. *et al.* (January and February 2017). *Community Based Screening Network: Combined HIV, Hepatitis and syphilis testing and monitoring – A community led partnership in Portugal*. Poster presented at HepHIV 2017, Malta.

Simões, D. *et al.* (July 2016). *Scaling up Standards, testing and linkage to care: implementation of a portuguese community-based network*. Poster presented at AIDS 2016, Durban, South Africa.

Previous page: ¹ UNAIDS, 2017.

³ Lisbon Regional Healthcare Authority, 2017.

¹ European Centre for Prevention and Disease Control, 2016.

⁴ ISPUP: Institute of Public Health of the University of Porto.

² Lisbon Regional Healthcare Authority, 2017.

➔ Behavioural and HIV prevalence study among MSM and transgender women in Ecuador

2016-2017 – Kimirina

Context

In Ecuador, MSM and transgender women are most affected by HIV, with prevalence rates of 16% and 35%¹, respectively. To stop this epidemic, it is crucial that the HIV epidemiology is closely monitored among these populations. To do so, Kimirina, together with the Ministry of Health, conducted a prevalence study that updated the available data on these two groups and described the situation of these highly exposed populations. The study aims to contribute to the development of specific HIV and STI prevention and therapy programmes.



Objectives

- Estimate the size of the MSM and transgender women populations in Ecuador;
- Assess the prevalence of HIV, syphilis, type 2 herpes simplex virus (HSV-2), and the hepatitis B (HBV) and C (HCV) viruses within these populations;
- Compare this prevalence data with the data collected in 2010 and 2012;
- Evaluate HIV knowledge among MSM and transgender women and document potentially risky behaviours, acquisition and transmission, serological status, and access to testing.

Methodology

- Sampling via the Respondent Driven Sampling (RDS) in Quito and Guayaquil;
- Behavioural data collected via questionnaire and collection of seroprevalence data based on blood sample collection for HIV, hepatitis B, hepatitis C, HSV-2, and syphilis tests.



Results

- HIV prevalence among the 748 MSM respondents was 17% in Quito and 11% in Guayaquil;
- HIV prevalence among the 206 transgender women respondents was 35% in Quito and 21% in Guayaquil;
- Condom use was dependent on the type of sexual relationship; it was more frequent with casual partners than with stable partners;
- The NGOs and healthcare services are known to a large proportion of MSM and transgender women for providing condoms, information and HIV tests;
- Stigma and discrimination continue to represent major barriers to prevention: 27% of transgender women reported humiliation, rejection, or verbal abuse due to their sexual orientation or gender by people they knew and didn't know.

Prevalence results highlighted the fact that MSM and transgender women are particularly affected by HIV in Ecuador. This information was integrated into the Ecuadorian Ministry of Health's 2017-2021 Strategic Plan.

¹ UNAIDS, 2017.



→ Integrated biological and behavioural surveillance survey and population size estimation among transgender women in the Republic of Mauritius

2017-2018 – PILS

Context

Since 2009, several integrated biological and behavioural surveillance (IBBS) surveys, as well as surveys on seroprevalence, have been conducted among the populations that are most exposed to HIV (MSM, sex workers, and IDU). In these surveys, transgender women were included among MSM; however, their potential exposure and vulnerability to HIV and other STI differ considerably — it is therefore recommended to sample them separately. Furthermore, IBBS surveys on MSM in 2010 and 2012 revealed that 4.7% and 14.2% of the participants identified themselves as transgender.

As a result, PILS and the Mauritian Ministry of Health launched a new IBBS survey in 2017, financed by the Global Fund and specifically addressing transgender women, to estimate population size and exposure to HIV, viral hepatitis, and other STI infections.



Objectives

- Measure the prevalence of HIV, HCV, and HBV, as well as associated potentially risky sexual behaviours among transgender women in the Republic of Mauritius;
- Provide socio-demographic data on hormone use and surgery to enhance femininity, on HIV knowledge, testing, intentions of taking PrEP, history of drug and alcohol use, stigmatisation, discrimination, arrests and violence.

Methodology

- Preliminary mapping of services available to transgender women and the identification of gaps between the needs and the availability of services;
- Study recruitment using a Respondent Driven Sampling (RDS);
- Face-to-face questionnaires completed in Port-Louis between August and September 2017, followed by pre-test counselling on HIV and a blood sample collection for HIV, syphilis, HCV, and HBV tests.



Results

- Among 109 transgender women respondents, HIV prevalence was 28%, syphilis prevalence 47%, and HCV prevalence was 18%;
- In the past 6 months, 40% of transgender women who had non-remunerated sex with a man (and 36% for remunerated sex) indicated systematic condom use;
- More than one quarter of the transgender women were sex workers; 27% of whom said that they never use condoms;
- 77% reported that they were usually the “receptive” partner during anal sex, which presents a higher risk of transmitting HIV and other STI;
- One third of transgender women had experienced stigma or discrimination, and 33% of them had attempted suicide;
- The majority of transgender women indicated that they had already taken an HIV test, but only 31% of them had been tested within the past 12 months and received their results;
- 65% of transgender women indicated that they were very likely to take PrEP if it was available;
- 97% of transgender women indicated that they would use rapid test kits if they were available.

This study led to a list of key recommendations that was presented during two workshops which gathered study stakeholders and the transgender community.

Scientific contribution

Publication of a report that provided data on the prevalence of HIV infections and the risk factors for transgender women. This report will be used as a reference by the Ministry of Health and PILS to monitor epidemic trends. Available on the PILS website: http://pils.mu/wp-content/uploads/2018/10/IBBS_TG_F.pdf.



**Access
to health
care**



Today, 41% of HIV-positive individuals across the world still do not have access to antiretroviral therapy¹. Scant economic resources and the fear of becoming a victim of serophobia discourage people from going to healthcare centres or from being tested. This injustice is all the more intolerable as the technical and scientific means to end AIDS already exist. It has been known since 2008 that an HIV-positive person on treatment, and whose viral load is undetectable, does not transmit HIV. As Coalition PLUS members are determined to build a world without HIV/AIDS, they are conducting studies on the conditions of healthcare access for people affected and infected by HIV/AIDS.



→ Study on the utilisation of healthcare services by people living with HIV in Cochabamba, Bolivia

2015 - IDH

Context

Since the beginning of the HIV epidemic in Bolivia, multiple human rights violations have been committed against PLHIV. All too often, such discrimination and stigmatisation has a health impact. In 2009, IDH carried out a knowledge, attitude, and practices (KAP) survey on HIV/AIDS. The results revealed an improvement of healthcare services in terms of medical care, diagnosis, and follow-up tests. However, this improvement falls short of ensuring quality care for PLHIV. To meet this challenge and to improve their access to healthcare services, a new study was carried out to better understand what encourages or discourages PLHIV from using HIV-specific healthcare services.



Objectives

- Describe the factors impacting the utilisation of healthcare services by PLHIV in Cochabamba, Bolivia;
- Identify barriers to healthcare access among PLHIV and develop solutions to remove them.

Methodology

- Semi-structured interviews and medical records review of 60 PLHIV (15 heterosexual women, 15 heterosexual men, 15 LGBT individuals, and 15 parents or legal representatives of children infected with HIV);
- A convenience sampling was developed with the hospital of Viedma, the CDVIR¹, and the Manuel Ascencio Villarreal children's hospital, with regard to 3 medical follow-up profiles: regular patients, irregular patients, and patients who dropped out of treatment.



Results

- Out of the 60 respondents, 22 were regularly monitored (37%), 23 irregularly (38%), and 15 had dropped out of treatment (25%);
- Regarding the quality of the healthcare services, parents of HIV-positive children were most satisfied, whereas LGBT individuals (8 individuals indicated that the quality was irregular) were least satisfied;
- 78% of the respondents thought that the antiretroviral therapy was efficiently controlling the virus and that it was therefore important to be monitored by a healthcare service for the treatment; 5% said that the treatment was toxic;
- 27% of respondents with regular follow-up needed less than an hour to reach the health centre. However, 25% of respondents with irregular follow-up and 12% of respondents who dropped out of treatment said that they needed between 1 and 2 hours to reach their healthcare centre;
- Among the people who irregularly use healthcare services or those who stopped using them, 21% indicated family reasons, 13% work-related reasons, and 13% indicated poor service quality;
- 8% of the respondents explained that they stopped going to healthcare services because of the distance to the healthcare centre, and 8% said that this was due to adverse effects of the ARV drugs.

One of the main factors impacting regular follow-up by PLHIV-specific healthcare services is the emotional relationship that PLHIV have with their families, friends, and partners. When this relationship is positive, it directly and positively influences the regularity of their treatment. This finding inspired a second study by IDH on ARV drug-taking and the emotional life. The results will be available in 2019.



“Community-based research represents a challenge, because it takes more time. You need to learn how to work together and to properly listen to the people. But if it’s well done, it offers true added value. For example, in this project, the community-based approach taught us more about the experiences of PLHIV, their perceptions, and their attitudes towards certain difficulties.”

Karina Rojas – Head of the Health and Human Rights Project – IDH

Scientific contribution

An article was published on the Revista Univalle platform: *Utilización de los servicios de salud por personas con VIH en Cochabamba, Bolivia* (Utilisation of healthcare services by people living with HIV in Cochabamba, Bolivia).

Previous page: ¹ UNAIDS – Global HIV statistics in 2017.

¹ Centro Departamental de Vigilancia y Referencia para VIH y sida (Departmental Center for Oversight and Reference for HIV and AIDS).



→ Tamkine – Study on the access to sexual and reproductive healthcare services by sub-Saharan migrant women in Morocco

2017-2018 – ALCS

Context

Since 2013, the migration policy in Morocco has taken a decisive turn with the first campaign to regularise migrants, especially those coming from sub-Saharan Africa. However, despite these regularisations, migrants coming from these countries with high HIV/AIDS prevalence rates find themselves in a vulnerable situation, which makes access to healthcare services more difficult. Women's sexual and reproductive health is particularly impacted.

As a result, ALCS, in collaboration with the Ministry of Moroccans Residing Abroad and Migration and the public organism Entraide Nationale, carried out a study on the access to sexual and reproductive healthcare services by sub-Saharan migrant women. The study was co-financed by the European Union and the Swiss Cooperation.



Objectives

- Identify the barriers to accessing medical, psychological, social and reproductive healthcare services for sub-Saharan migrant women in Morocco;
- Identify the barriers to accessing HIV/AIDS treatment for these women;
- Develop solutions for changing public structures in order to eliminate these barriers.

Methodology

- A quantitative survey conducted using a Respondent Driven Sampling (RDS) in Rabat-Salé-Kenitra, Casablanca and Oujda;
- A qualitative survey via 16 focus groups (composed of migrant women, staff from the healthcare system and NGO representatives) and 170 semi-structured interviews (118 with migrant women, 44 with staff from the healthcare system, and 20 with NGO representatives). The survey was conducted in Rabat-Salé-Kenitra, Casablanca, Fez, Oujda and Agadir.



Results

- 1,000 sub-Saharan migrant women were recruited between November 2017 and January 2018;
- Limited financial resources, language barriers, fear of stigmatisation and-or discrimination and the illegal status of migrants were declared to be the main barriers to accessing sexual and reproductive healthcare services, as well as pregnancy follow-ups;
- Difficulties of accessing medication, discrimination, remoteness of healthcare structures and long waiting times for medical consultations were declared as the main barriers to accessing healthcare and HIV/AIDS care services. •



“The community-based research has renewed the enthusiasm of ALCS’s volunteers and employees! It is a new and original approach, which they find particularly rewarding as it echoes their own needs and concerns and relies on their expertise. Furthermore, this approach provides information and results that directly concern them. Several members have clearly committed themselves to their work with ALCS because of these research programmes. We can no longer imagine working without community-based research!”

Amal Ben Moussa – Director of Research Projects – ALCS



TB-Check – A study on the barriers to tuberculosis diagnosis and healthcare services among intravenous drug users (IDU) in Romania

2017-2018 – ARAS

Context

In 2016, Romania was one of 18 priority countries in the fight against tuberculosis, having the highest incidence among southeastern European countries (84 new cases per 100,000 inhabitants¹). Despite significant progress during the last several decades, the eradication of tuberculosis remains difficult in this country as the population most affected by this illness does not systematically seek assistance from diagnosis and/or treatment services.

The operational “TB-check” study among IDU in Bucharest identified and analysed the obstacles to accessing these services. It built on the work carried out by the organisations ARAS, ALIAT, and Parada within the project “Treatment for everyone – Now!” (2015 to 2018 in Bucharest). The Romanian Angel Appeal Foundation coordinated the study and it was financed by the Global Fund to Fight AIDS, Tuberculosis and Malaria.



Objectives

- Identify the reasons why IDU did not go to the diagnosis and treatment services they were referred to by social workers of ARAS’s and ALIAT’s tuberculosis risk reduction programmes;
- Analyse personal experiences, knowledge and attitudes regarding tuberculosis among IDU in Bucharest.

Methodology

- A quantitative survey conducted by ARAS’s and ALIAT’s mobile teams to measure the efficiency of the three different methods for referring IDUs, who had not had a chest X-ray in the past six months, to tuberculosis diagnostic centres: a simple referral, an accompanied referral, and a simple referral with vouchers;
- A qualitative survey to understand the differences regarding the efficiency of the three referral methods:
 - Focus groups with IDUs who use the risk reduction services at the ARAS Titan permanent centre, and who have not been x-rayed in the past 6 months (9 individuals);
 - Individual interviews with IDU who have already been diagnosed with tuberculosis and who have accessed or are accessing treatment services (7 individuals).



Results

- The simple referral with vouchers method was the most efficient: 56% of IDU who were referred according to this method presented to the tuberculosis diagnostic centres. The simple referral method had an 8% efficiency rate, and the accompanied referral method was not efficient at all;
- 84% of IDU reported hepatitis C infection, and 41% said they were HIV-positive;
- The most cited reasons for agreeing to an x-ray were a fear of death, a desire to live and the wish to have a family. The main reasons for refusing to get an x-ray were a lack of internal resources (motivation) and external resources (family support), the influence of drugs, and the priority of finding the financial means to buy substances according to their addiction;
- The negative self-perception of their physical appearance and the level of personal hygiene were often mentioned as decisive factors for not having medical examinations.

The “TB-check” study helped understand to what extent IDU were involved in their health and identified ways of providing better support for their care. The study helped community actors adapt their messages in order to more effectively meet the needs of IDUs.



“When we began this project on tuberculosis screening and treatment among IDU, I could never have imagined the problems we would encounter with the beneficiaries, who consistently refused to be accompanied to their tuberculosis testing. Neither the initial training nor the intervention manual written by the specialists at the beginning of the project could have prepared me for what we found on the ground. The “TB-check” community-based research revealed efficient intervention methods that may prove to be useful for other healthcare referral activities with this population. The results we obtained using both a scientific and a community-based approach reflect the reality that our team encountered on the ground.”

Monica Dan – Project coordinator – ARAS

Scientific contribution

A report is in the process of being drawn up.

¹ WHO/Europe, 2017.



➔ CohMSM – The prevention of HIV infection among MSM in sub-Saharan Africa: feasibility of and interest in a global preventive healthcare offer provided on a quarterly basis

2015-2020 – ARCAD-SIDA

Context

In West Africa, the prevalence of HIV is estimated at 15% among MSM compared to 1-3% among the general adult population^{1,2,3}. Despite this high risk of infection, few adapted prevention and healthcare programmes are available for this group. Due to a lack of sufficient studies in this population, the actual effectiveness of this type of intervention and of current HIV prevention programmes is not known.

With financing from ANRS and Initiative 5%, the project CohMSM was coordinated by the Research Institute for Development, in collaboration with the community organisations ARCAD-SIDA in Mali, AAS in Burkina Faso, EVT in Togo, Espace Conscience in the Ivory Coast, Coalition PLUS, and SESSTIM.

⊕ **Objectives**

The general objective of the project was to assess the feasibility and interest in a global preventive healthcare offer provided on a quarterly basis to MSM in Abidjan (Ivory Coast), Bamako (Mali), Lomé (Togo), and Ouagadougou (Burkina Faso), in order to help reduce HIV incidence among this population, its female partners, and the general population.

Methodology

- An interventional, open, multi-centre and multi-disciplinary cohort study;
- The participants received global healthcare services on a quarterly basis, including:
 - a. collection of information regarding their health, STI symptoms, and the individual's sexual behaviours;
 - b. a clinical examination;
 - c. HIV testing for HIV-negative individuals and treatment for HIV-positive individuals;
 - d. diagnosis and treatment of STI;
 - e. counselling sessions;
 - f. provision of condoms and lubricants.

Additionally, vaccination against the Hepatitis B virus (HBV) and annual tests for syphilis were offered;

- 700 MSM — 500 HIV-negative individuals and 200 HIV-positive individuals — who were at least 18 years old and who had any anal sex (active or passive) with another man over the past 3 months were recruited and followed for 24-36 months.



Preliminary results

The results presented below are not comprehensive as most results are still being analysed:

- As of May 31, 2018, 630 HIV-negative participants and 183 HIV-positive participants were included;
- On March 9, 2018, 93% of the HIV-positive MSM started ARV treatment within 7 days on average;
- Of the 769 MSM (618 HIV- and 151 HIV+) included in the study in January 2018, and who were tested for HBV, the prevalence of HBV was 11.2 per 100 persons per year. 92% of the participants received at least one dose of vaccine.
- Of the 564 HIV-negative MSM included between June 2015 and June 2017, 87% were interested in PrEP, especially those who reported anal sex without systematic condom use, those who had transactional sex, those who looked for sexual partners online, and-or those who already had an STI upon joining the CohMSM study;
- Of the 729 HIV-negative and HIV-positive MSM included between June 2015 and June 2017, 96% were highly satisfied with their peer educators and 41% contacted a peer educator at least once outside their scheduled visits.

Scientific contributions

Pierre-Julien Coulaud *et al.* (2018). *Interest for HIV pre-exposure prophylaxis by men who have sex with men in West Africa (CohMSM ANRS 12324 – Expertise France)*. Tropical Medicine and International Health. doi:10.1111/tmi.13129.

Couderc C. *et al.* (2017). *Is PrEP Needed for MSM in West Africa? HIV Incidence in a Prospective Multicountry Cohort*. *Journal of Acquired Immune Deficiency Syndromes*, 75(3):e80-e82.

Elias Dah *et al.* *Hépatite B chez les HSH infectés ou non par le VIH en Afrique de l'Ouest : prévalence, facteurs associés et acceptabilité de la vaccination (CohMSM ANRS 12324 – Expertise France)*. Oral presentation AFRAVIH 2018, Bordeaux, France.

¹ Beyrer C *et al.* Global epidemiology of HIV infection in men who have sex with men. *Lancet* 2012,380:367-377.

² Papworth E *et al.* Epidemiology of HIV among female sex workers, their clients, men who have sex with men and people who inject drugs in West and Central Africa. *J Int AIDS Soc* 2013,16:18751.

³ UNAIDS. Global report on the AIDS epidemic. 2013 (October 4, 2013); Available from: http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2013/gr2013/UNAIDS_Global_Report_2013_en.pdf.

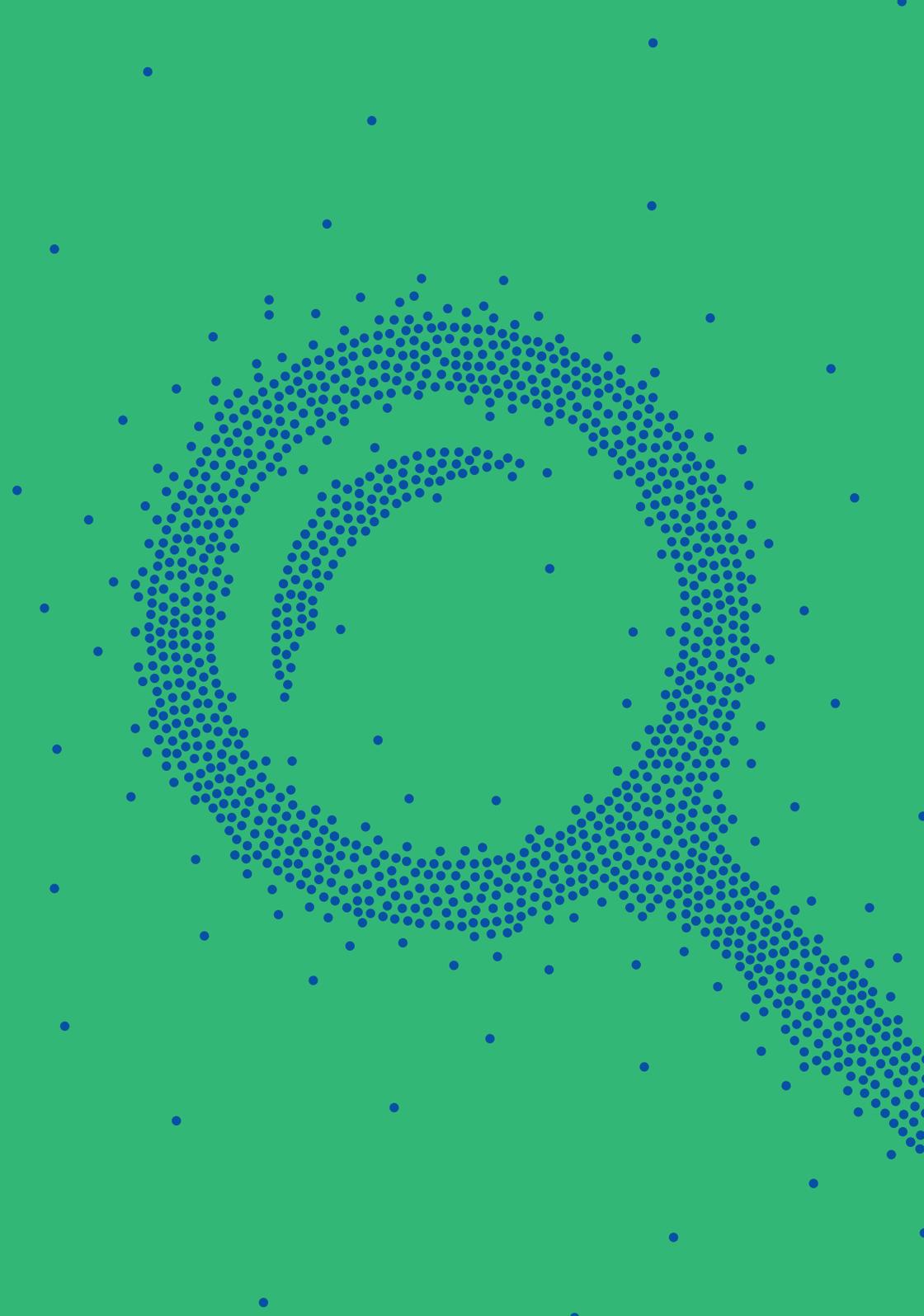
CohMSM-PrEP: the first PrEP research project with MSM in West Africa!

The “CohMSM-PrEP” project, which was launched in November 2017 and will last for 3 years, is part of, and completes, the CohMSM program. It seeks to assess the acceptability and feasibility of PrEP for MSM as part of a combined prevention programme at CohMSM’s 4 non-profit clinics. CohMSM-PrEP is an interventional, open, multi-disciplinary and multi-centre study. All MSM benefit from a combined prevention programme, which includes quarterly clinical examinations, STI testing and treatment, HIV testing, PrEP (daily or upon request), HBV vaccination, individual support by peer educators, support groups, and provision of condoms and lubricants.



“Before PrEP was implemented, many CohMSM participants asked when it would be available. Before launching the CohMSM-PrEP project, we started to raise awareness in our community. Most of the participants then said they were willing to take PrEP. Before, peer educators had to look for participants for the CohMSM study, but now, people come spontaneously. When PrEP was available, many people started to take it.”

Diarra, Ali and Drissa – Peer educators for the CohMSM-PrEP project



Living

HIV



with

Every day, our organisations deal with HIV and viral hepatitis epidemics that are concentrated among populations that are highly stigmatised and marginalised by society. The sexual and mental health of these individuals is impacted even more when discrimination and repression keep them from healthcare structures and from social spheres. To provide a better quality of life to PLHIV, Coalition PLUS is conducting studies to understand and monitor the development of this kind of discrimination. In accordance with the “Zero Discrimination” goal set out by UNAIDS, our organisations work to ensure that these individuals no longer have to hide because of their HIV-positive status.



Stigma Index – A study on the different experiences of stigma and discrimination faced by people living with HIV in the Republic of Mauritius and in Morocco

2016-2017 – ALCS and PILS

Context

The People Living with HIV Stigma Index is an initiative developed and implemented by and for PLHIV. It aims to collect information on the experiences of stigma, discrimination, and human rights among PLHIV in the form of an index. It follows the joint initiative of several organisations: The Global Network of PLHIV/AIDS (GNP+), the International Community of Women Living with HIV/AIDS (ICW), the International Planned Parenthood Federation (IPPF), and the United Nations Program on AIDS/HIV (UNAIDS). It was designed to be adopted by different groups in different communities, countries and continents, and it is used as a tool for local, national, and international advocacy to ensure that PLHIV's fundamental rights are respected. This tool is crucial for developing initiatives that deal with HIV-related stigma and discrimination. Its interest is two-fold as it allows to compare countries and to study developments within a country if the study is repeated over time.

Since its creation in 2008, it has been taken up in more than 90 countries, including the Republic of Mauritius in 2013 and Morocco in 2017. In the Republic of Mauritius, the Stigma Index study was conducted by PILS, in partnership with the Ministry of Health, with the financial support of the Global Fund and the technical support from the Global Network of PLHIV.

In Morocco, the Stigma Index study was carried out by ALCS in collaboration with the Ministry of Health, UNAIDS and the Global Fund.



Objectives

- Document the stigma and discrimination that PLHIV face because of their serological status by their relatives and their community;
- Measure the perceived discrimination and the actual discrimination when accessing services such as healthcare and education, or at the workplace;
- Study the impact of stigma on internal fears and how they affect PLHIV's decision-making;
- Study PLHIV's knowledge and understanding of their rights and the laws that affect them;
- Study PLHIV's experiences regarding HIV testing, diagnosis and treatment, as well as sexual and reproductive healthcare services;
- Study experiences of HIV status disclosure and confidentiality among PLHIV;
- Compare PLHIV's situations in different countries;
- For PILS, study the evolution of the stigma and discrimination affecting PLHIV in Mauritius since the 2013 survey.

Methodology

- Translation and adaptation of the questionnaire into local languages (Arab dialects and English creole) and training interviewers living with HIV to carry out the survey;
- Survey conducted between March-June 2016 using the cluster sampling method at 8 health-care centres in Morocco, and between October-November 2017 using the snowball sampling method in Mauritius.



Results – ALCS, Morocco

- In total, 624 PLHIV were recruited -300 of them were men (48%) and 324 were women (52%);
- 31% of the women and 23% of the men reported being excluded from social activities such as weddings, funerals, and-or parties;
- 21% of the women and 14% of the men reported being excluded from daily activities such as cooking, eating together and-or sleeping in the same room;
- 62% of the respondents reported being ashamed, and 21% had thought about committing suicide because of their HIV-positive status;
- Due to these feelings of guilt and shame, 45% of the respondents decided to isolate themselves from family and friends, and 52% said that they avoided going to regional health-care centres.

The study results were presented at a workshop on the 2018-2021 national strategy on human rights and HIV/AIDS organised by the Moroccan Ministry of Health, in collaboration with the National Human Rights Council. The recommendations of the Stigma Index study were taken into consideration in the development of the new national strategy.



Results – PILS, Republic of Mauritius

- 415 PLHIV were recruited, 268 of whom were men (65%), 130 were women (31%), and 17 (4%) were transgender;
- 42% of the respondents had low self-esteem, 37% felt guilty, and 37% were ashamed of their HIV-positive status;
- 55% of the respondents associated the stigma and discrimination with their drug use, 24% with their status as former prisoners, and 17% with sex work;
- 41% of the respondents avoided regional health centres; 32% were afraid that the healthcare professionals would disclose their status without their consent and 30% were afraid of being discriminated by them because of their HIV status;
- Only 38% of the respondents consulted a healthcare professional for HIV treatment in the first three months after their diagnosis; 30% took more than one year to do so, and 4% had not yet started their medical care and follow-up;
- 27% of the respondents decided not to get married, and 14% decided to stop having sex because of their HIV status.

Following this project, a report was published for the stakeholders (the Ministry of Health, members of the PLHIV community, PILS members, partner organisations, etc.) which documents and measures the development of the stigma and discrimination that PLHIV face in Mauritius and compares it to other countries in the world.

➔ Respect Portugal – Knowledge, attitudes, and behaviours of healthcare professionals in primary healthcare facilities regarding HIV and the populations most exposed to HIV in Portugal

2015-2018 – GAT

Context

HIV infection remains a major public health problem in Portugal (9.5 new cases per 100,000 inhabitants in 2017¹). In this context, access to treatment and healthcare for infected individuals is crucial to fight this epidemic. Moreover, HIV-positive individuals face stigma and discrimination on a daily basis. In the medical domain, these factors contribute to keeping HIV-positive individuals from all types of care, especially primary healthcare. As part of the European Union-funded “OptTEST” project on “Stigma and legal barriers to the provision and use of HIV testing services,” GAT, in partnership with Ser+, conducted a study on the knowledge and behaviours of healthcare professionals towards people affected and infected by HIV.



Objectives

- Identify the barriers and obstacles associated with the stigma and discrimination of people affected by HIV by healthcare professionals;
- Design strategies to promote and increase early diagnoses.

Methodology

- Self-administered questionnaire completed by healthcare professionals in 3 primary health-care centres in the Lisbon metropolitan area (physicians, nurses and psychologists);
- The questionnaire focused on socio-demographic characteristics, HIV knowledge, attitudes towards PLHIV and the affected populations, HIV testing, and practices of health-care professionals.



Results

- 167 healthcare professionals participated in the survey;
- 30% of the respondents thought that HIV could not be passed on through breastfeeding, 60% thought that it was transmissible by saliva, 75% thought that it was transmissible by kissing on the mouth. 36% thought that it was transmissible by sharing clothes and 8% thought that it was transmissible by skin contact;
- 50% of the respondents felt at risk of infection doing their job, 77% when giving primary care to infected individuals and 38% during gynaecological examinations;
- Only 45% were aware of the national HIV guidelines and 79% of them did not know how to implement them;
- 40% of professionals systematically wore gloves with HIV-positive patients, 9% a mask;
- 16% of physicians informed the partners of HIV-positive individuals without their consent;
- 77% of respondents did not have any HIV training over the past 5 years.

The analysis of the survey data allowed the GAT Anti-Discrimination Centre to set up trainings for healthcare professionals. A second questionnaire will assess the impact of this training on the practices of healthcare professionals towards PLHIV.

¹ Data from the Portuguese National Program on HIV Infection, AIDS, and Tuberculosis, 2017.



➔ A comparative study among people living with HIV in Bolivia: therapeutic education to achieve an undetectable viral load²

2012-2016 – IDH

Context

Several studies have shown that an undetectable viral load prevents HIV transmission. For the patient, this is an indicator of the treatment's success and directly improves his or her life. For the community and for public health, this is a cornerstone of the strategy to end the HIV/AIDS epidemic by 2030. An undetectable viral load necessarily depends on proper treatment adherence, which in turn depends on several factors, such as therapeutic education. Based on the "practical guide for therapeutic education for healthcare professionals" drawn up in 2012 by IDH with the support of BfDW¹, IDH conducted a study to measure the impact of therapeutic education in achieving an undetectable viral load.

Objectives

- Determine the effectiveness of therapeutic education with regard to antiretroviral treatment adherence in order to achieve an undetectable viral load among IDH patients;
- Compare the percentages of patients with an undetectable viral load who participated in the therapeutic education program and who did not participate;
- Determine the factors associated with treatment adherence (illness perception, life projects, self-esteem, adverse drug effects, and access to treatments) in both study groups.

Methodology

- A comparative, longitudinal study conducted from July 2012 to June 2015 among PLHIV using a convenience sampling (individuals recently diagnosed in Cochabamba and receiving medical care at IDH);
- During the process, 6 follow-up evaluations were carried out to monitor the antiretroviral treatment adherence;
- The first and final follow-up visits included a questionnaire to determine the participant's general characteristics (age, gender, socio-economic status, level of education, marital status) and social characteristics (level of HIV/AIDS knowledge, self-esteem, family support, support group membership, life projects, perception of HIV/AIDS and alcohol use);
- A laboratory test (treatment adherence, CD4 count and viral load) and a clinical review (regularity of consultations, hospitalisations, adverse drug effects) at each follow-up visit.

Results

- 44 people were interviewed — 22 had undergone a therapeutic education program, the other 22 had not (68% were men and 32% were women, according to the epidemiological profile of the HIV epidemic in Bolivia);
- 95% of those who participated in the program achieved an undetectable viral load at the last follow-up session, compared to 68% of those who did not participate in a therapeutic education program. The percentage of PLHIV with an undetectable viral load between the first and the second follow-up session increased by 45% among the people who participated in the program compared to 31% among those without any therapeutic education;
- Of those who participated in the program, men achieved a higher percentage of undetectable viral load (50% compared to 33% among women).

In addition to confirming the effectiveness of therapeutic education in terms of treatment adherence, the study highlighted the importance of this strategy to end the HIV/AIDS epidemic, especially in times when financial resources for healthcare are limited.

Scientific contribution

Valdez Carrizo E. *et al.* (2016). *A comparative study among patients infected with HIV: therapeutic education as a way to achieve an undetectable viral load* (Estudio Comparativo Entre Pacientes con VIH: Educación Terapéutica Para Alcanzar Una Carga Viral Indetectable). *Rev. Inv. Inf. Salud.* vol.11, n.28 [citado 2018-06-15], pp. 11-22. ISSN 2075-6194.

¹ Pan Para el Mundo, Alemania (Bread for the World, Germany).

➔ *Témoigner pour Agir:* scientific, artistic and associative knowledge regarding the diverse realities of sexual and gender communities in Quebec, Canada

2015-2018 – COCQ-SIDA

Context

Since 2005, COCQ-SIDA, a Coalition PLUS member in Quebec, has participated in the various “VIHsibilité” research-action projects conducted by the University of Quebec in Montreal. They sought to understand the discourse on HIV/AIDS and to implement an action plan to change the situation. In 2011, the projects led to the creation of the “Testimonial Cultures” research group, which brought together various communities represented by the Groupe de recherche et d’intervention sociale (The Research and Social Intervention Group (GRIS-Montreal))¹, Stella², l’amie de Maimie (Stella), the Center for Gender Advocacy (the Center)³ and COCQ-SIDA.

Despite their differences, lesbian, gay, bisexual, transgender, intersexual, queer, and questioning individuals who live with HIV or who have sex work experience, all have in common that they are relegated to the margins of society, out of fear, due to the ignorance or prejudice of others. They constantly face stigma, discrimination and social prejudice. Moreover, sex workers and PLHIV in Canada can be criminalised because of their work or for not disclosing their HIV-positive status when having sex.

This long collaboration on using testimonials as a social and cultural intervention strategy led to the *Témoigner pour Agir* art exhibition, which was created by and for people belonging to groups that are marginalised because of their sexuality, gender, or body. The exhibition was financed by PAFARC⁴ and CRSH⁵.



Objectives

- Enhance knowledge among various audiences of sexual and gender communities' diverse experiences and their individual as well as collective stories;
- Share scientific knowledge, the expertise of artists and community actors, and the public;
- Create an ethical, aesthetic and political discourse on the issues, challenges and consequences of providing a testimony of one's sexuality, gender, work, body, and HIV status;
- Support the social inclusion of sexual and gender communities by creating favourable conditions for disclosing their HIV status and improving their living conditions.

Methodology

- 3 focus groups with 10 individuals recruited by partner organisations and the ASSTeQ⁶ group to design and set up the exhibition with members of the concerned populations (in 2015);
- A steering committee, a body composed of members of the partner organisations, responsible for considering the ethical issues specific to the exhibition to ensure human diversity and dignity;
- A call for projects and works of art for the exhibition to partner organisations and other allied agencies that also work with sexual and gender communities, as well as on the Facebook page of the "Testimonial Cultures" research group (in 2016);
- The criteria adopted by the steering committee for the selection of works of art were as follows:
 - Prioritising artists who tell their own personal story through their art and who express a commitment to the diversity and plurality of marginalised voices;
 - Prioritising works that do not convey prejudice and that offer non-stigmatising representations;
 - The exhibition's message has to be a source of empowerment;
 - No restrictions on the media.



Results

- The activities took place over a 6-week period, from November 29, 2017 to January 21, 2018;
- There were 3 main sites in Montreal: the Maison de la culture Frontenac, the Bibliothèque Frontenac library and the University of Quebec in Montreal;
- In total, 2,000 people visited the exhibition.

¹ A community-based organisation whose mission consists of enhancing knowledge of homosexual and bisexual realities and facilitating the social integration of gay, lesbian and bisexual people.

² A community-based organisation that works to improve the quality of life and working conditions for sex workers and to educate society on the various forms and realities of sex work so that sex workers have the same rights to healthcare and safety as the rest of the population.

³ An independent organisation that promotes gender equality and autonomy, especially within marginalized communities.

⁴ The financial aid programme for research and creation. Research in the context of community-based services, Phase 2 (2015-2016) of the Service to Communities at the University of Quebec in Montreal (SAC-UQAM).

⁵ Subventions Connection (2017-2018) of the Canadian Humanities Research Council (CRSH).

⁶ *Action Santé Travesti-e-s et Transsexuel-le-s du Québec*, also known as "Québec Trans Health Action".



**Cultures du témoignage,
Témoigner pour Agir : Voir,
S'engager, Changer.**

Photo:
Jamie Goodyear, 2017.

**Groupe de Recherche et d'Intervention
Sociale (GRIS-Montréal).**

Une histoire à la fois..., 2017.

Mixed media, 120 × 120 cm.

Témoigner pour Agir, 2017, Montreal.

Photo:
Jamie Goodyear, 2017.

Richard Sawdon Smith

The Anatomical Man (L'homme anatomique), 2009.

Photographic series, giclée inkjet prints, triptych: left and right, 50,8 × 33, centre 55,1 × 33 cm. *Témoigner pour Agir*, 2017, Montreal.

Photo:
Jamie Goodyear, 2017.





Government's gay purge 'odious,' PM pounces

OTTAWA (CP) — Prime Minister Justin Trudeau on Monday said the government's decision to purge gay, lesbian and transgender members of the Canadian Forces was "odious" and "discriminatory."

Trudeau said the government was "not going to let anyone be treated differently because of their sexual orientation or gender identity."

The prime minister said the government was "not going to let anyone be treated differently because of their sexual orientation or gender identity."

Discriminating service

Canadian Forces has problems dealing with gay personnel

OTTAWA (CP) — A senior Canadian Forces officer said the military has "problems" dealing with gay personnel, a statement that could be seen as a sign of discrimination.

The officer, who spoke on condition of anonymity, said the military has "problems" dealing with gay personnel, a statement that could be seen as a sign of discrimination.



YOU HAVE NO PLACE HERE

Lesbian says false accusation ended string of advancements

OTTAWA (CP) — A lesbian officer in the Canadian Forces says a false accusation ended her career. She says she was accused of having a sexual relationship with a superior officer.

The officer, who spoke on condition of anonymity, said she was accused of having a sexual relationship with a superior officer. She says she was accused of having a sexual relationship with a superior officer.

BY CAMPBELL MORRISON

Associate Defence

OTTAWA (CP) — Mary Collins, a lesbian officer in the Canadian Forces, says she was accused of having a sexual relationship with a superior officer.

Collins said she had never had a sexual relationship with the officer. She says she was accused of having a sexual relationship with a superior officer.

BY PETER HAYS

The Daily News

Keitha Cortes is waiting out the last days of a once-promising military career she says

Armed and gay

Homosexuals in the military face an uneasy welcome

OTTAWA (CP) — A 36-year-old supply technician in the Canadian Forces says he has been "outed" by a superior officer. He says he has been "outed" by a superior officer.

The technician, who spoke on condition of anonymity, says he has been "outed" by a superior officer. He says he has been "outed" by a superior officer.



The 36-year-old supply technician in the Canadian Forces says he has been "outed" by a superior officer. He says he has been "outed" by a superior officer.

The technician, who spoke on condition of anonymity, says he has been "outed" by a superior officer. He says he has been "outed" by a superior officer.



Michelle Douglas, ruled that the longstanding ban on homosexuals contravened the Charter of Rights and Freedoms. Since then, headquarters staff in Ottawa have been drafted.

Michelle Douglas, ruled that the longstanding ban on homosexuals contravened the Charter of Rights and Freedoms. Since then, headquarters staff in Ottawa have been drafted.

Kevin Crombie
Gloss/Vernis, 2017.

Photo:
Jamie Goodyear, 2017.

Artist's book, 22,9 x 29,2 cm.
Témoigner pour Agir, 2017, Montreal.



**Stella, l'amie de Maimie
et Chloé Surprenant.**

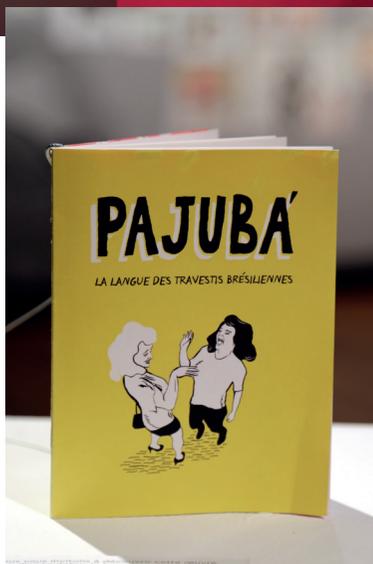
La pièce rose, 2017.

Installation, 243,8 × 365,8 cm.

Témoigner pour Agir, 2017, Montreal.

Photo:

Jamie Goodyear, 2017.



Eloisa Aquino

Pajubá, 2014-17.

Fanzine, 30 × 30 cm.

Témoigner pour Agir, 2017, Montreal.

Photo:

Jamie Goodyear, 2017.

This project has had an impact on several levels⁷:

- *Témoigner pour Agir* has contributed to the enhancement and development of academic, artistic and community knowledge about public testimony as a social intervention strategy, from the perspective of inclusion, social transformation and representation of sexual and gender communities in all their diversity;
- From an academic point of view, the exhibition and its programming provided a space for learning and development. Six students of varying degrees were hired and integrated into the team, contributing to the development of their research skills, mainly related to knowledge mobilisation and dissemination;
- The benefits for the general public are numerous: people had access to testimonies of unfamiliar realities, the opportunity to ask questions and to debate, to inform themselves and to become more aware of the importance of including sexual and gender communities. Participation in the *Témoigner pour Agir* exhibition was a major event for certain audiences as it was the first time many people heard stories of sexual and gender communities and were invited to break out of prevailing prejudices.

Finally, an evaluation is being carried out on how the exhibition had been received by the three main audiences who came to visit: the general public, the sexual and gender communities and the media. The evaluation “seeks to determine its intervention potential for fighting discrimination and stigmatisation”⁸. It uses the same collaborative principles and governance that were used for setting up the exhibition.



Even today in Canada, young people in LGBTQ2S⁹ communities, those living with HIV, or who have sex work experience, are more at risk than other young people of being victims of hate crimes or of committing suicide. This risk increases even more when the individual belongs to a racialised or indigenous group. Yes, even today. Because these individuals are often stereotyped, harassed and intimidated. For some, testimony then becomes an important strategy to exist.”

Maria Nengeh Mensah – Researcher for the project *Témoigner pour Agir*

Scientific contribution

Mensah, Maria Nengeh, Laura Gagnon, Laurie Fournier, Jamie Wilson Goodyear et Geneviève Chicoine (June 2018). Final report on the outreach activities. *Témoigner pour Agir*: see, make a commitment, change.

^{7,8} Excerpts from the final report.

⁹ LGBTQ2S : Lesbians, gays, bi, transgender, queer, two-spirited.





A final word

This brochure presents an overview of all the community-based research work that Coalition PLUS member organisations have carried out in recent years. These collective efforts have contributed to the international development of community-based research.

The projects that are presented in this brochure confirm the importance and relevance of involving the people concerned in all stages of the research, from the identification of the research topic to the dissemination of the results. This involvement ensures the appropriation of the results by the concerned populations and the implementation of relevant field interventions that meet people's needs. It is a fundamental condition for achieving the social transformation sought by the community-based approach as it enables the evolution of the rights of concerned individuals.

The Community-based Research Department of Coalition PLUS continues to promote this approach among the approximately 40 member and partner organisations. The Department provides technical support that is adapted to their needs and facilitates the development of joint projects that stimulate the collective, international dynamic that is dear to Coalition PLUS.

Several community-based research projects are currently being developed on a wide range of topics, such as access to PrEP, the profiles and needs of male sex workers, and improving medical care as well as the access to medical care after community screening. They are all multi-country projects and involve several member organisations of Coalition PLUS. The strength of our network will allow us to collect global and comparative data, and thus support advocacy at the regional and international level. The results will be published in the next edition of this brochure.

“Over the last 10 years, Coalition PLUS has been using the community-based approach for research. For a decade, we have been sharing our knowledge and our skills to promote socially useful research that focuses on people and their needs - research that is able to guide field interventions and to provide data for an advocacy that is still needed. We believe in the end of AIDS! But we also know that it can't happen without the communities. Together, we can now accomplish what seemed impossible 10 years ago.”

Daniela Rojas Castro

Director of Community-based Research – Coalition PLUS



Acronyms

ANRS

French National Agency for Research on AIDS and viral hepatitis.

ARV

Antiretroviral drugs.

DU

Drug user.

HBV

Hepatitis B Virus.

HCV

Hepatitis C Virus.

HIV

Human Immunodeficiency Virus.

IDU

Intravenous drug user.

INSERM

French National Institute of Health and Medical Research.

LGBT

Lesbian, gay, bisexual, and transgender.

MSM

Men who have sex with other men.

PLHCV

People living with hepatitis C virus.

PLHIV

People living with HIV.

PrEP

Pre-exposure prophylaxis.

STI

Sexually transmitted infections.

SW

Sex worker.

UNAIDS

United Nations Program on HIV/AIDS.

UNICEF

United Nations Children's Fund.

WHO

World Health Organization.

Glossary

Buprenorphine (or Subutex®) is an opioid substitution treatment that allows individuals to reduce their opiate consumption without experiencing withdrawal effects. Although administered as tablets, some people on treatment reported that they inject it without medical supervision, which may be a risk to their health.

CD4 cells are the immune cells that are attacked and destroyed by HIV. HIV infection leads to the progressive reduction of CD4 cells, their count is therefore used to assess disease progression and drug efficiency.

Cluster sampling consists of dividing a study population into subgroups (also called “clusters”), each representative of the original study population. A number of clusters are randomly selected to represent the total population, and their units are then included in the sample.

Convenience sampling is a population sample selected according to criteria of convenience, accessibility and cost.

A focus group (or collective interview) is a qualitative survey technique that brings together a small group of people, selected according to specific criteria, in a planned discussion on various topics.

HIV incidence is the number of new HIV infections over a given period of time.

HIV prevalence is the percentage of HIV infected people within a given population.

PrEP (Pre-exposure prophylaxis) is a HIV prevention tool that consists of the administration of antiretroviral drugs. PrEP is therefore for HIV-negative people.

Respondent Driven Sampling (RDS) combines “snowball sampling” with a mathematical model that balances the sample in order to compensate for the fact that the sample was collected in a non-random manner.

A semi-structured interview is a qualitative survey technique that partially guides the interviewee’s speech around various topics that have been defined in advance by the interviewers and recorded in an interview guide.

Snowball sampling is a method for recruiting study participants, especially for so-called “hard to reach” populations. It consists of several recruitment rounds. The first round is composed of a few members of the study population. These individuals are then asked to indicate other people in their network who meet the study criteria. These persons are then contacted in a second round. The process is repeated until the desired sample size is reached.

Therapeutic education refers to all the assistance provided to the patient to help him-her better manage his-her illness and is therefore an integral part of the patient’s medical care.

A transgender individual is a person who lives or wishes to live with a different gender identity than the one assigned to her or him at birth. This includes anyone who has made or wishes to make a transition, whether or not they choose to undergo medical or surgical treatments for this purpose. For example, a transgender woman is a person who was assigned “male” at birth, and who transitions to a “female” gender.

Treatment adherence is the adequacy between the patient’s and the physician’s perceptions regarding the relevance of the treatments. Adherence refers to individual and collective notions of the treatments. It is distinct from **treatment compliance**, which refers to practices, i.e. taking drugs according to medical prescription.

Viral load is the amount of virus found in the body fluids of an infected person. When it is low (less than 20 copies/ml), it is considered undetectable and the HIV virus can no longer be transmitted to sexual partners.

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