



PRESS KIT

ANRS | Emerging Infectious Diseases committed to community-based research

For science built around community needs

Scientific Information and Communication Department
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EDITORIAL

This year we will continue to provide our support to the International AIDS Society (IAS) for the AIDS 2022 international conference, which will take place between July 29 and August 2 in Montreal. As part of this event, we will hold a [symposium on July 29 regarding community-based research](#), which is the central theme of this press kit.

At ANRS | Emerging Infectious Diseases, community-based research forms part of a jointly led scientific approach in which community stakeholders are involved at every step, from the design of the project to the communication of the results.

Choosing community-based research is not just about fostering dialogue and collaboration between researchers, patients, and associations, it is also about thinking, co-constructing, and implementing projects to address the problems and needs of communities and society. Without the involvement of civil society and of affected people, research would be incomplete.

Joining this co-construction dynamic also enables us to take into account, recognize, and legitimize people living with HIV and affected community's experience as an information source crucial to the advancement of scientific knowledge. They are central to the research mechanisms; they are stakeholders in guiding the medical, social, and political decisions that concern them.

Choosing community-based research is also about going beyond the evaluation of medicinal products and devices: it is about reflecting on how they will be put to use in real life. Something that would be impossible without the expertise and field knowledge of the community stakeholders, and particularly the associations.

The development of community-based research forms an integral part of ANRS | Emerging Infectious Diseases' strong commitment to its collaboration with civil society and associations.

In the fight against HIV and viral hepatitis, the associations, along with TRT-5 CHV, have proved themselves essential players. This collaboration is central to how ANRS | Emerging Infectious Diseases operates.

Over time, associations, NGOs and community representatives have joined the agency's scientific committees and governance bodies to contribute to strategic and programmatic decisions.

This is a characteristic of the functioning of the ANRS | Emerging Infectious Diseases model. It is an institution that involves community players right from the design stage of the projects so that they best align with target populations and are deployed quickly and efficiently.

For example, ANRS-IPERGAY, a study demonstrating the efficacy of on-demand pre-exposure prophylaxis (PrEP) in the prevention of HIV, was developed with a group of partner associations involved in the LGBT sphere and the fight against AIDS. Placed under the joint responsibility of academia and the association AIDES, the project has marked an important milestone in community-based research into HIV, and its findings have considerably influenced national and international recommendations concerning PrEP.

Other examples of community-based research are presented in this kit.

Of course, no collaboration is perfect: there is always room for improvement.

While this cooperation has proven itself in the fight against HIV and viral hepatitis in France and in the agency's partner countries, we are committed to continue forging closer links with NGOs and communities, including in the field of emerging infectious diseases. In order to perpetuate this model, which is a strength, we are working to expand our network, particularly at international level. This is a priority for ANRS | Emerging Infectious Diseases over the coming years.

Establishing new cooperations with associations demonstrates our desire to continue to structure our actions around the needs of communities and take each voice into account.

Véronique Doré, head of the ANRS | Emerging Infectious Diseases Department of Public Health and Human and Social Sciences

Yazdan Yazdanpanah, director of ANRS | Emerging Infectious Diseases





Makasi

Strengthening the sexual health empowerment of Afro-Caribbean populations to facilitate access to social and health structures in Île-de-France

The migration pathway of sub-Saharan and Caribbean populations is often long and laborious. The precariousness in which they live - caused by migration policy-related structural and administrative factors - when arriving in France puts them at additional risk of contracting HIV. The Makasi project was designed to address this issue. In Lingala, Makasi means "strong", "dynamic", and "powerful". This carefully chosen term clearly illustrates the aim of this project, which is to promote the empowerment of sub-Saharan African and Caribbean immigrant populations living in precarious situations so that they can take ownership of and implement the means of prevention and care needed to reduce their exposure to sexual risks.

As a project that gives a key place to the involvement of association representatives, Makasi was developed in collaboration with [Afrique Avenir](#), whose aim is to raise awareness among African and Caribbean populations living in Île-de-France regarding sexual risks, and [ARCAT](#), which offers legal and social support to people living with HIV in precarious situations.

The involvement of these two associations throughout the project and the experience they provided have made it possible to develop an initiative that is both relevant and adapted to the realities of the communities in question.

Makasi perpetuates the [PARCOURS survey](#), carried out in Île-de-France between 2012 and 2013 among immigrants from sub-Saharan Africa.

Its results had shown that:

- among people from sub-Saharan Africa living with HIV, nearly half (35 to 49%) were infected following their arrival in France rather than in their home country;
- being in a precarious situation - undocumented, homeless, unemployed - increases the risk of exposure to HIV;
- it generally takes a long time for people from sub-Saharan Africa to get established in France, with several years needed to become free from precariousness and the attendant exposure to HIV.

OBJECTIVES

Makasi is an interventional research project aimed at reducing overexposure to HIV by supporting, informing, and raising awareness among sub-Saharan and Caribbean populations, in order to strengthen their capacity to take informed action on their sexual health according to these four dimensions:

- capacity to express their needs;
- competence in sexual health;
- self-esteem;
- awareness of exposure to HIV and STIs.

To achieve this, the study teams decided to reach out to the populations through an external intervention in the Paris region, led by the mobile units of the Afrique Avenir association.

In order to reach as many people as possible, the intervention targeted busy thoroughfares (street, station, subway exits, markets...) frequented by the sub-Saharan African and Caribbean populations. This enabled them to refer immigrants in precarious situations and exposed to sexual risks to the appropriate health and social services. Following a personalized motivational interview with a health mediator, actions to raise awareness regarding sexual health and perform HIV and hepatitis C screening were also undertaken.

Together, researchers and associations have defined the context and content of the intervention, its implementation and evaluation conditions, the data collection and communication tools in order to reach the target individuals and explain the approach. From the start of the project, the associations also formed a community committee (made up of people affected by the project, namely immigrants born in sub-Saharan Africa and having experienced social, economic, and administrative difficulties during their establishment in France) which, together with researchers and associations, participated in constructing the intervention and its evaluation.

Annabel Desgrées du Loû – IRD research director, member of the Population and Development Center and deputy director of the Convergences Migrations Institute, principal investigator of the study.

In order to evaluate this intervention, the research teams opted for a mixed methodology enabling them to carry out a quantitative evaluation of the impact and a qualitative evaluation of the processes.

ANRS-Makasi has made it possible to mobilize the specific expertise and know-how of ARCAT and Afrique Avenir to propose an intervention capable of globally understanding the situation of immigrants regarding screening actions in order to address the social and administrative factors that prevent their inclusion and maintenance on the care pathway.

Nicolas Derche – director of ARCAT, director of the Kiosque Infos Sida & Toxicomanie and regional director of the SOS Group

This project has enabled the transfer of skills between the two associations, which are now fully integrated into the projects developed by them.

Romain Mbiribindi – managing director of Afrique Avenir

This project was the subject of a nine-month pilot phase in 2018, followed by two years of intervention during which 849 people were enrolled. The results are expected in the second half of 2022. Some have already been presented at AFRAVIH 2022.

ANRS-Makasi was funded by ANRS | Emerging Infectious Diseases and the Regional Health Agency.

TO FIND OUT MORE

ANRS-Makasi project website
<https://www.projet-makasi.fr/>

Focus on ANRS-Makasi, a sexual health empowerment project
<https://www.anrs.fr/fr/actualites/957/focus-sur-makasi-un-projet-dempowerment-en-sante-sexuelle>



2DM2K – Dou Dèmè Muso Ka Keneya

Health and migration pathways of female home helps in Bamako

2DM2K is a project that forms part of a community-based research study developed in collaboration with the [SantéRCom health and community-based research team of the SESSTIM](#) (Aix-Marseille University, Inserm, IRD) JRU1252. In order to ensure feasibility and focus on the most appropriate way to reach the target community, [ADDAD](#) – an association defending the rights of home helps and domestic staff – and [ARCAD Santé PLUS](#), were fully involved in the project design.

2DM2K studies the health-related knowledge, attitudes, beliefs, and behaviors of home helps in a context of vulnerability related to cyclical migration. It also evaluates the acceptability of prevention and care provision integrated in ADDAD's activities in Mali.

Its name, "Dou Dèmè Muso Ka Keneya", comes from Bambara and means "promoting the health of female home helps and domestic staff".

In Mali and other West African countries, the phenomenon of internal migration follows the climate cycle marked by a rainy season (June to September) and a dry period (October to May). This temporary labor-related migration primarily concerns those in a situation of socio-economic precariousness, which include home helps who during these migration periods are exposed to a hostile environment that makes them vulnerable to health problems.

They are often exposed to violence (physical, psychological, and sexual) and sex work, placing them at increased risk of infection. Precarious living conditions that are often provided by their employers also expose home helps

to other communicable diseases (tuberculosis and COVID-19).

OBJECTIVES

This is the context of the 2DM2K project. In order to better understand the situation of vulnerable populations, particularly home helps, the project aims to:

- document living conditions in the towns and villages of origin of these women, the reasons for their migration, and their living and working conditions in Bamako;
- reconstruct the migration pathway of the home helps and understand the place of ADDAD in their current living and working conditions in terms of protection of their rights;
- take stock of the health situation (including sexual health) and evaluate the acceptability of prevention and care provision in the community;
- identify the home helps concerned by cyclical geographic mobility and study the link between this mobility and the potential geographic displacement of communicable diseases such as HIV, STIs, hepatitis, and tuberculosis.

2DM2K was designed on the basis of the routine activities of ADDAD and ARCAD Santé PLUS, with the collaboration of SESSTIM for the community-based research component. The research-related activities were carried out according to the seasonal migration cycle of the home helps, between their village of origin and Bamako.

The project consists of several stages:

- a preliminary qualitative survey based on the implementation of seven focus groups including between 42 and 56 home helps;
- planned awareness-raising and communication activities in the regions of origin of the home helps;
- planned awareness and communication activities in Bamako and community activity days held by ADDAD including community-based care provision offered by ARCAD Santé PLUS.

During these days, the home helps will be offered a medical consultation. Screening for HIV, hepatitis B and C, and tuberculosis will be available in the event of clinical signs or contact with someone infected with tuberculosis.

Sexually active home helps can also have a rapid pregnancy test, if pregnancy is suspected, as well as a vaginal sample to screen for bacterial, fungal, and viral infections.

Between 42 and 56 home helps are expected for the preliminary qualitative survey, 1134 for the cross-cutting quantitative survey, and 25 for the qualitative survey based on individual interviews.

“*The vulnerability of temporary labor migrants, particularly female home helps, is exacerbated by poor knowledge of communicable infections, underestimation of risks, limited access to prevention, and reduced use of prevention methods.*”

Bintou Dembélé Keita – co-investigator of 2DM2K, director of ARCAD Santé PLUS in Mali.

“*Dou Dèmè Muso Ka Keneya will enable a better understanding of the specific problems and needs of the home helps concerned by the labor migration they are obligated to undergo in Mali. The results of this project will also make it possible to develop mechanisms of access to prevention and care that is adapted to their daily reality.*”

Louis Sagaon Teyssier – co-investigator of 2DM2K, IRD research officer.

Awareness-raising activities in the villages will begin in September 2022 and the quantitative survey will take place between January and May 2023. The results are expected for the end of 2023.

2DM2K is funded and sponsored by the agency and developed in collaboration with JRU1252 SESSTIM.

FURTHER READING

Meeting with Bintou Dembélé Keita on the care of women living with HIV in Mali and West Africa

<https://www.anrs.fr/fr/actualites/1022/rencontre-avec-bintou-dembele-keita-sur-la-prise-en-charge-des-femmes-vivant-avec>



CohMSM

The value of comprehensive care provision in preventing HIV among men who have sex with men (MSM) in West Africa

In West Africa, while the prevalence of HIV is relatively low in the general population (1.4%), it is estimated at 13.3% among MSM, a population that is both vulnerable and little studied. Launched in 2013, the CohMSM program was designed to evaluate the feasibility, acceptability, and value of comprehensive care in preventing HIV in this key population.

Community stakeholders are strongly involved in implementing this project, whose initial results have led to the adaptation of national programs to combat HIV/AIDS.

CohMSM is a multidisciplinary, operational research program on the prevention and care of HIV/AIDS among MSM in West Africa, implemented in community association clinics in Burkina Faso, Côte d'Ivoire, Mali, and Togo.

A total of 1211 MSM were included in this study, 956 of whom HIV-negative. HIV-negative MSM have a diversified prevention offering that includes HIV screening every three months and pre-exposure prophylaxis (PrEP). HIV-positive MSM are offered antiretroviral therapy (ART) upon diagnosis.

All volunteers are offered screening and treatment for STIs, vaccination against hepatitis B, personalized peer-educator support (prevention counseling, help with treatment compliance, and psychosocial support), as well as condoms and lubricant.

The results of this project have shown the benefit of the quarterly HIV screening, prevention advice, PrEP, and rapid antiretroviral

therapy initiation in HIV-positive MSM in Africa. Bintou Dembélé Keita, managing director of ARCAD Santé PLUS and co-principal investigator, specifies that *"this new data has facilitated the inclusion of PrEP in national HIV/AIDS programs in the countries where the study took place"*.

A large number of association partners are involved in this project: **Coalition PLUS** (France), **African Solidarité** (Burkina Faso), **Espace Confiance** (Côte d'Ivoire), **ARCAD Santé PLUS** (Mali) and **Espoir Vie Togo**, in collaboration with the **TransVIHMI JRU** (IRD, Inserm and Montpellier University), the **SESSTIM JRU** (IRD, Inserm and Aix-Marseille University), the **Institute of Tropical Medicine in Antwerp** (Belgium) and the **BIOLIM** laboratory of the University of Lomé (Togo).

The associations involved in this project are all pioneers in the fight against HIV/AIDS, having for many years conducted targeted prevention, screening, and care activities for MSM in collaboration with national HIV/AIDS programs.

They actively involve MSM in these activities. They play a major role in informing and mobilizing their peers, as well as in recruiting, welcoming, guiding and monitoring CohMSM participants.

They also facilitate community councils composed of members of the local MSM community that offer a space for expression, sharing and communication between beneficiaries, health-care providers, and the African and European CohMSM teams.

“*These community players have been able to develop leadership in the fight against HIV/AIDS in this population.*”

Christian Laurent – co-principal investigator of the study, IRD research director

CohMSM is funded and sponsored by the agency and co-funded by Expertise France.



TO FIND OUT MORE

HIV prevention: efficacy of pre-exposure prophylaxis in West Africa confirmed

<https://www.anrs.fr/fr/presse/communiqués-de-presse/839/prevention-du-vih-efficacite-confirmer-de-la-prophylaxie-pre>

HIV: socio-economic factors limit PrEP efficacy in MSM in West Africa

<https://www.anrs.fr/fr/actualites/1081/vih-des-facteurs-socioeconomiques-limitent-lefficacite-de-la-prep-chez-les-hsh-en>

FOCUS ON...

CohMSM and Prévenir: two neighboring community-based research projects

The CohMSM program is very close to the [Prévenir cohort study](#), which confirmed that [on-demand pre-exposure prophylaxis \(PrEP\) is an alternative that is just as effective and safe as daily PrEP in preventing HIV in France](#). It was conducted in partnership with associations, thanks to the involvement of AIDES/Coalition PLUS and Le 190 and Checkpoint Paris in the recruitment and support of volunteers, in conjunction with the scientific teams from AP-HP, Inserm, Paris Cité University, Sorbonne University, Aix-Marseille University and IRD. Prévenir has provided new evidence in favor of adding on-demand PrEP to the HIV prevention offering and has led to its approval by WHO for MSM.



DRIVE – *Drugs & Infections in Vietnam*

How to achieve the eradication of HIV, hepatitis C and tuberculosis and screen for and treat mental disorders among people who inject drugs in Haiphong, Vietnam

Since 2014, ANRS, in collaboration with the US NIDA and the Global Fund, has supported the Vietnamese government's initiative to reduce HIV transmission among people who inject drugs (PWID), a group at high risk of infection with HIV and other pathogens, via the ANRS partner site in Vietnam.

DRIVE has demonstrated for the first time that it is possible to eradicate HIV transmission in a resource-limited context thanks to community intervention. This project has led to the creation of a multidisciplinary research platform in Haiphong, in partnership with the local authorities and civil society.

This platform has provided the basis for the development of other community studies targeting public health priorities for PWID, based on a strategy to eradicate hepatitis C, control tuberculosis, and identify and manage common mental disorders in the same population. This HIV model has been translated and replicated as a program of interventions supported by the Global Fund since 2021, in five provinces of Vietnam, and extended to include men who have sex with men (MSM).

OBJECTIVES

DRIVE aims to eradicate the HIV epidemic among PWID in Haiphong with the help of community intervention, which includes a repeated mass screening approach (using respondent-driven sampling – RDS) conducted at community sites, and peer support in facilitating access to antiretroviral therapy (ART), methadone and risk reduction initiatives. All in all, over 3000 volunteers were exposed to the community intervention, 25% and 66% of whom were seropositive for HIV and hepatitis C,

respectively. While 79% of the PWID were already receiving ART and had an undetectable viral load, DRIVE made it possible to effectively treat around half of the seropositive PWID who were not on treatment at inclusion (Nagot et al. *Lancet Regional Health Western Pacific* 2022, in press). This intervention was accompanied by a very low incidence of HIV (<0.5%), showing that it is possible to put an end to the HIV epidemic among PWID in a resource-limited country.

DRIVE is conducted by Duong Thi Huong (Faculty of Public Health, Haiphong University of Medicine and Pharmacy) and Nicolas Nagot (JRU1058, Pathogenesis and Control of Chronic and Emerging Infections (PCCEI), Montpellier University, Inserm, EFS, Antilles University, Montpellier)

DRIVE-C

Part of the DRIVE research program, the DRIVE-C study (fully funded by the agency) evaluated the efficacy of a hepatitis C (HCV) screening and treatment model among PWID, in order to eradicate HCV transmission within this population. Of the 1201 PWID identified with hepatitis C, 979 began treatment with sofosbuvir/daclatasvir and 901 (92% of those having started treatment) were cured, with follow-up showing a low rate of reinfection after one year.

DRIVE-C has shown that mass screening in the community, combined with an integrated, decentralized care model and large-scale community involvement (especially to reduce risks and harms), enables the eradication of HCV in this very high-risk group.

DRIVE-C is conducted by Prof. Pham Minh Khuê (Faculty of Public Health, Haiphong University of Medicine and Pharmacy) and Dr. Didier Laureillard (JRU1058, Pathogenesis and Control of Chronic and Emerging Infections, Montpellier, Nimes University Hospital, coordinator of the ANRS Vietnam partner site)

DRIVE-MIND

The DRIVE-MIND study (also funded by the agency and part of the DRIVE research program) evaluated the impact of community-based psychiatric intervention among PWID with medical support from the Department of Mental Health at Haiphong University Hospital. Enrolled in the DRIVE cohort, eligible participants were offered psychiatric care at community sites. In this context, the study showed better adherence to psychiatric care (which was zero with the usual care provision), significant clinical benefit, improved quality of life, and a reduction in the stigma associated with psychiatric disorders despite only a marginal reduction in drug use.

DRIVE-MIND is conducted by Dr. Sao Mai Le (psychiatrist in the Department of Mental Health of the Haiphong Faculty of Medicine and Pharmacy) and Dr. Laurent Michel (director of the Pierre Nicole Center and researcher at Inserm)

DRIVE-COVID

Finally, the DRIVE-COVID study, funded by the agency, showed that care services for PWID had been maintained during the COVID-19 pandemic and that there was no increase in the number of HIV and HCV infections. However, the impact of the health crisis has nevertheless exacerbated the social situation of the most vulnerable groups, including PWID and sex workers, promoting certain practices that put them at risk of HIV and HCV infection.

DRIVE-COVID is conducted by Dr. Delphine Rapoud (JRU1058, Pathogenesis and Control of Chronic and Emerging Infections, Montpellier) and Giang Hoang Thi (Haiphong University of Medicine and Pharmacy)

DRIVE-TB

In the future, the DRIVE-TB project will aim to control the tuberculosis epidemic among PWID in Haiphong, one of the two main causes of mortality in this population. This intervention, which will use the community approaches of DRIVE (community screening, referral to care), will be conducted in collaboration with Vietnam's national tuberculosis control program, the Haiphong University of Medicine and Pharmacy, local community-based organizations, and SCDI ("Supporting Community Development Initiatives" the national NGO). It will be sponsored by the agency as well as funded by the agency and Expertise France.

A key partner in this program, the Vietnamese association SCDI, directed by Dr. Khat Thi Hai Oanh, aims to support a range of Vietnamese community associations across the country, improve the quality of life of the most vulnerable populations, which include PWID, sex workers, people living with HIV (PLHIV), their partners and their children. The NGO is active in raising awareness about drug use and drug users, while promoting more inclusive and human rights-based policies. Its role was to coordinate the activities of the seven local community-based organizations which played a key role in the design and implementation of the DRIVE research program projects.

DRIVE was jointly coordinated by Prof. Don Des Jarlais (New York University School of Global Public Health), Prof. Nicolas Nagot (JRU1058 Montpellier), Prof. Duong Thi Huong (Haiphong University of Medicine and Pharmacy), and Dr. Khat Thi Hai Oanh (SCDI).

The agency is co-funding the DRIVE research program in Haiphong, with the US NIDA and the Global Fund.

FOCUS ON...

DRIVE, a program that inspired the ICONÉ study in Montpellier

The ICONÉ study took inspiration from the DRIVE methodology to achieve the goal of eradicating HCV among drug users in France.

In the city of Montpellier, ICONÉ evaluated the efficacy of a community model for the mass screening of HCV by RDS, combined with the immediate initiation of treatment, on the improvement of the HCV care cascade among active drug users. Peer users employed by the study took part in all stages of the research, particularly in the support and follow-up of HCV treatments. 554 participants were enrolled in 11 weeks, 8.8% of whom had a detectable viral load for HCV. The results confirm the efficacy of this strategy in the eradication of HCV, with the initiation of antiviral treatment for 37 of the 49 users screened with hepatitis C, and a cure confirmed for 27 of them (55%).

This study was conducted by Dr. Hélène Donnadieu (JRU1058 and Department of Addiction Medicine at University Hospital Montpellier) in collaboration with the SOS Solidarités Group.

Several medical and association stakeholders took part, including the CAARUDs ("La Boutik" – Réduire les Risques and "Axess"), the CSAPAs (AMT-Arc-en-Ciel and UTDD), and Avitarelle, which posted experienced staff as a means of supporting access to social rights and in the care of drug users and were able to identify users ("seeds") for launching the study. The association SOS-hépatites provided support for the recruitment and training of peer employees.



SEXTRA

For a better understanding of cisgender male and transgender male and female sex workers and their sexual health needs in eight countries

SEXTRA is a multi-country, exploratory and descriptive study to identify the determinants of HIV and the sexual health needs of cisgender male and transgender male and female sex workers who use the Internet to find their clients. This community-based research project will provide new data on a population that is not yet well studied.

Few studies have focused on cisgender male and transgender male and female sex workers, a population that is difficult to reach for prevention stakeholders. Some data suggest that around 10% of cisgender male sex workers and 27% of transgender female sex workers are infected with HIV, with differences between countries and regions.

SEXTRA seeks to identify risk factors for HIV infection and to better understand the sexual health needs of sex workers who use the Internet to find partners with whom to exchange sex for money, services, or other goods.

The study consists of an exploratory and descriptive cross-cutting survey, using an online questionnaire that collects information on sociodemographic characteristics, high-risk sexual behaviors with commercial and non-commercial sexual partners, risk reduction strategies, psychoactive substance use, stigma, and access to health (including knowledge about HIV and STIs, prevention and care). Since the launch and conduct of the study were affected by the COVID-19 crisis, the data collection tools have also taken this context into account.

In order to take into account different cultural, social, and political contexts, the study is taking place in eight countries: Bolivia, Canada, Ecuador, France, Morocco, Portugal, Republic of Mauritius, and Romania.

The study is led by Daniela Rojas Castro (director of the Coalition PLUS community-based research laboratory) and Edgar Valdez (director of the Instituto para el Desarrollo Humano in Cochabamba, Bolivia). SESSTIM (Aix-Marseille University, Inserm, IRD) is also involved in the project as scientific partner.

Coalition PLUS, a network bringing together over 100 HIV/AIDS and hepatitis associations, is coordinating the actions of local associations: AIDES in France, ALCS in Morocco, GAT in Portugal, Kimirina in Ecuador, IDH in Bolivia, PILS in Mauritius, REZO in Canada, and ARAS in Romania.

“ Involving local associations in this project is essential in order to reach cisgender male and transgender male and female sex workers, rendered invisible by their online activity and who are victims of stigma and discrimination. ”

Daniela Rojas Castro – director of the Coalition PLUS community-based research laboratory

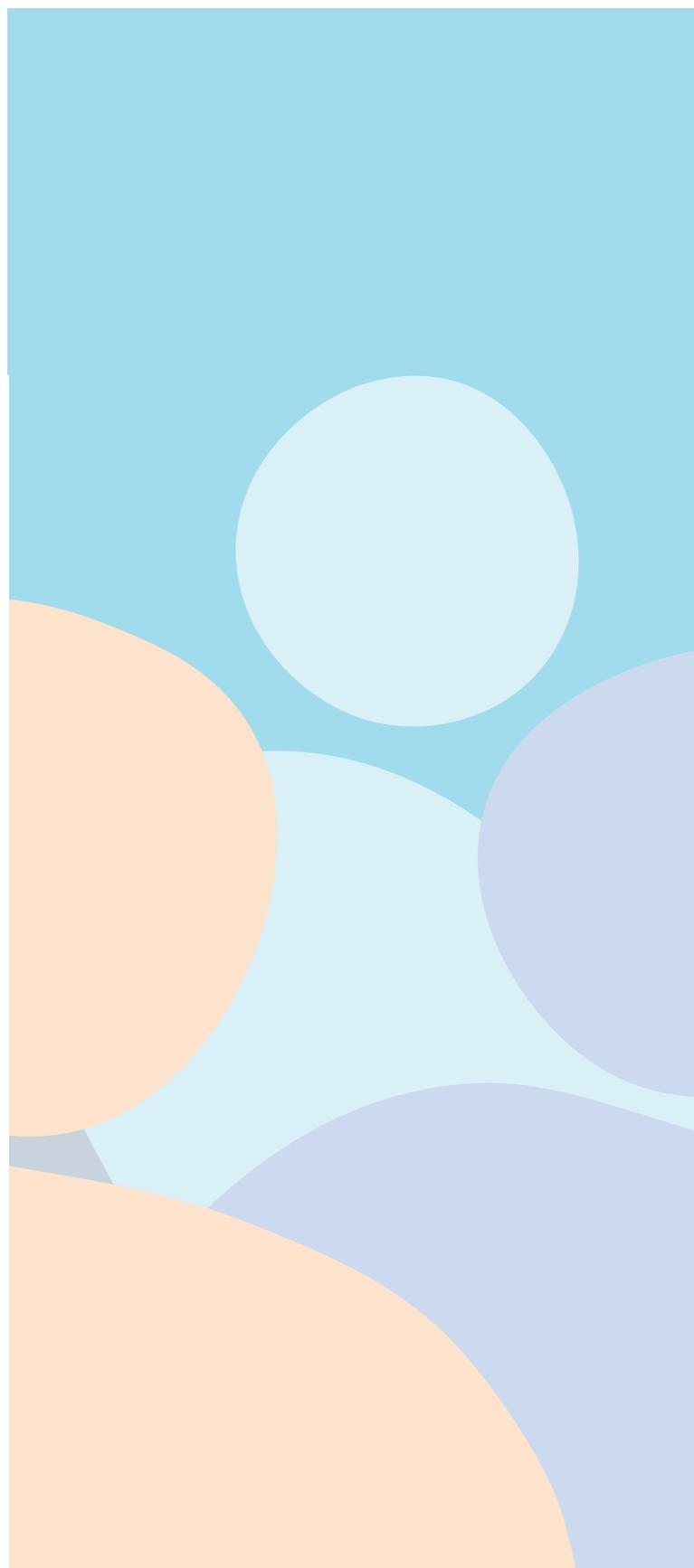
The community stakeholders and sex workers take part at all stages of the project.

Data was collected between June 2021 and June 2022. During this period, the local teams implemented various strategies for distributing the questionnaire. From banners posted on dating apps to promotion in community screening centers, each team designed and implemented relevant strategies according to the local context, adapting them as participant recruitment progressed. Over 1700 people in total completed the online survey. The data collection phase is now finalized, and the participating teams are beginning to prepare and analyze the initial results.

They will be used to guide the development and adaptation of interventions to meet the health needs of cisgender male and transgender male and female sex workers who use the Internet to find their clients. This exploratory research will also generate ideas for future research projects concerning this population.

ANRS | Emerging Infectious Diseases is sponsoring and funding this study.

The results are expected by 2023.





CONCLUSION

Without collaboration between researchers and community stakeholders, none of the projects presented in this kit could have been possible.

They demonstrate that the involvement of community stakeholders, particularly associations, from project design to implementation, is essential and enables the production of impactful research findings. This model applied to the fight against HIV/AIDS has already proved its worth and continues to do so.

It may also be beneficial for other diseases associated with social and societal issues in order to fight misinformation and promote transparent, participatory, and committed research. During the COVID-19 pandemic, many criticisms were made regarding the lack of citizen involvement in the decisions made about their health.

At ANRS level, this need has been taken into account. The new associations, which during the health crisis had made the voices of those concerned heard, have been involved in order to establish and conduct research projects together. For example, during the preparation of COCOPREV – a project to develop COVID-19 treatments for patients at high risk of severe forms – the kidney disease patient association Renaloo was involved.

By working closely together, civil society representatives and the academic world mutually enrich each other and pool their expertise with the one same objective: to improve prevention, screening, patient care – including the most vulnerable, and public health policies to benefit society as a whole.

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