



**epic**

Surveys to Assess  
the Impact  
of the COVID-19  
Health Crisis at the  
Community Level

the challenges of  
community-based research in  
the context of the health crisis

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## Project origin

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At the start of the COVID-19 pandemic, information on the various community-based initiatives employed to carry out their comprehensive care activities was limited. It was thus necessary to document the new solutions and adaptations put in place (telemedicine, home delivery of ARV, use of social networks and online platforms to support and help vulnerable persons access health services and maximize their safety and protection against the new coronavirus, etc.). "Flash" surveys were put in place by the Coalition PLUS community-based associations to better identify the needs of users as well as the additional measures and/or necessary readjustments to actions initiated in response to the COVID-19 health crisis. Various survey dynamics formed within the network, which the Research and Strategic Innovation Department (DRIS) supported through the EPIC program. A joint working group was created, composed of **researchers** (Santé Publique France, INSERM, AP-HP, Public Health England, Faculdade de Ciências Médicas da Santa Casa de São Paulo) and **community health workers** from within the members of Coalition PLUS (ARCAD Santé PLUS in Mali, ALCS in Morocco, AIDES in France, Kimirina in Ecuador, PILS in Mauritius and ANSS in Burundi).

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## The project

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The "**EPIC**" program (Surveys to Assess the Impact of the COVID-19 Health Crisis at the Community Level) is a community research program (multi-country study) designed in March 2020 within the context of the COVID-19 pandemic.

To respond to the initiatives put in place in very different contexts, DRIS drew up a **general protocol for the EPIC program** based on the work of a Working Group and several joint construction and consultation meetings, **with the following aims:**

- Study the impact of the COVID-19 health crisis on key populations - men who have sex with men, transgender (trans) people, sex workers, people who use drugs, people living with HIV, migrants - vulnerable to HIV and/or HCV and on people working with these populations in a community setting (peer educators, carers, etc.);
- Identify the key innovations and adaptations in HIV/HCV services that could be maintained and extended beyond the COVID-19 health crisis.

## KEY RESULTS OF THE EPIC PROGRAM

(April 2020 - Feb. 2023)

Production of scientific and strategic knowledge to evaluate the impact of COVID-19 on users from key populations and community health workers within Coalition PLUS associations, on their needs and the actions put in place by the different structures participating in this study in response to the COVID-19 (and post-COVID-19) health crisis

**More than 200 people involved** in conducting these surveys

**10 languages** used (English, French, Spanish, Portuguese, Arabic, Romanian, Malay, Mauritian Creole, Kirundi and Tetum)

**77 structures<sup>1</sup> mobilized in 32 countries** in Africa, North, Central and South America, Asia, Europe and the Middle East – including 2 thematic networks mobilized (RIGHT PLUS and the Lusophone network), 7 geographic networks (MENA, PFAO, PACE, PFAC, PFOI, PF SASEA, PFE)

Integration of the EPIC program into pre-existing cohorts

Mobilizing of funding

**119 surveys of 13,352 respondents**

PLUS (Mali), ANPROSEX (Brazil), ABGLT (Brazil), APROSBA (Brazil), APROSMIG (Brazil), Coisa de Puta (Brazil), Coletivo Por Elas Empoderadas (Brazil), Associação Mulheres Guerreiras (Brazil), CUTS (Brazil), Foiesp (Brazil), GEMPAC (Brazil), Grupo de mulheres prostitutas do Estado do Pará (Brazil), Jovens Unidos por Direitos Iguais e Humanos (Brazil), Movimento de Prostitutas no Brasil (Brazil), NEP (Brazil), NHUDES (Brazil), RGP (Brazil), Tulipas do Cerrado (Brazil), Coletivo de Pesquisa em Antropologia e Saúde (Brazil), Escuela de Salud Pública de la Universidad de Chile (Chile), Fundación SAVIA (Chile), ASPF (São Tomé), Ass vida (São Tomé), ATL (Tunisia), ATP (Tunisia), Bésyp (Benin), CAS (Guatemala), CEEISCAT (Spain), Stop. (Spain), CISSS (Peru), Espace Confiance (Côte d'Ivoire), Espoir Vie Togo (Togo), GAT (Portugal), Hatutan (East Timor), IpDH (Bolívia), Warmis (Bolívia), Kindlimuka (Mozambique), Kuyakana (Mozambique), MATRAM (Mozambique), Abevamo (Mozambique), MAC (Malaysia), University of Malaya (Malaysia), Unidos (Mozambique), MARSÁ (Lebanon), PILS (Mauritius), SOS PE (Mauritania), VERDEFAM (Cape Verde).

1. APCS (Algeria), AniSS (Algeria), CDR-CHU Annaba (Algeria), MWENHO (Angola), Amigos positivos (Colombia), Cimientos de Luz (Colombia), Corporación El Faro (Colombia), FUDAVIDA (Colombia), Fundación OAH (Colombia), Fundación Shaddai (Colombia), Fundaroma (Colombia), FUNSEC (Colombia), IFARMA (Colombia), Prodihogar (Colombia), Recolvih (Colombia), RED SOMOS (Colombia), Temeride (Colombia), TOMS (Quebec, Canada), COCQ-SIDA (Quebec, Canada), Montréal sans sida (Quebec, Canada), AAS (Burkina Faso), REVS PLUS (Burkina Faso), ADPP (Guinea-Bissau), RENAP (Guinea-Bissau), AIDES (France), ALCS (Morocco), AMAR (Argentina), Casa Trans (Argentina), ATTTA (Argentina), Fundación Huésped (Argentina), ANCS (Senegal), ANSS (Burundi), ARAS (Romania), ARCAD Santé

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## Aims of capitalization

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1

Provide the keys to a better understanding of what the process, design and implementation of such a program involves;

2

Identify, analyze and valorize the achievements and the results obtained, the success factors and levers for success, as well as the innovations developed;

3

Identify the challenges, difficulties and lessons learned; identify the conditions for success of a community-based research project;

4

Contribute to the production of strategic knowledge;

5

Valorize the ability of Coalition PLUS to mobilize and take action through its networks and its community-based approach.

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## Capitalization methodology

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A review of the project tools and documents

Semi-structured interviews with two members of the Coalition PLUS DRIS team, researchers, and coordinators/research officers from several Coalition PLUS structures

Meetings and e-mail correspondence for reminders of the specific topics identified during the interviews

Midway feedback: workshop, questionnaires (DRIS and network coordinators/officers)

# Definition of community-based research according to the program stakeholders

According to the EPIC program stakeholders – representatives of community-based associations – **community-based research** is an approach centered on quality and scientific ri-

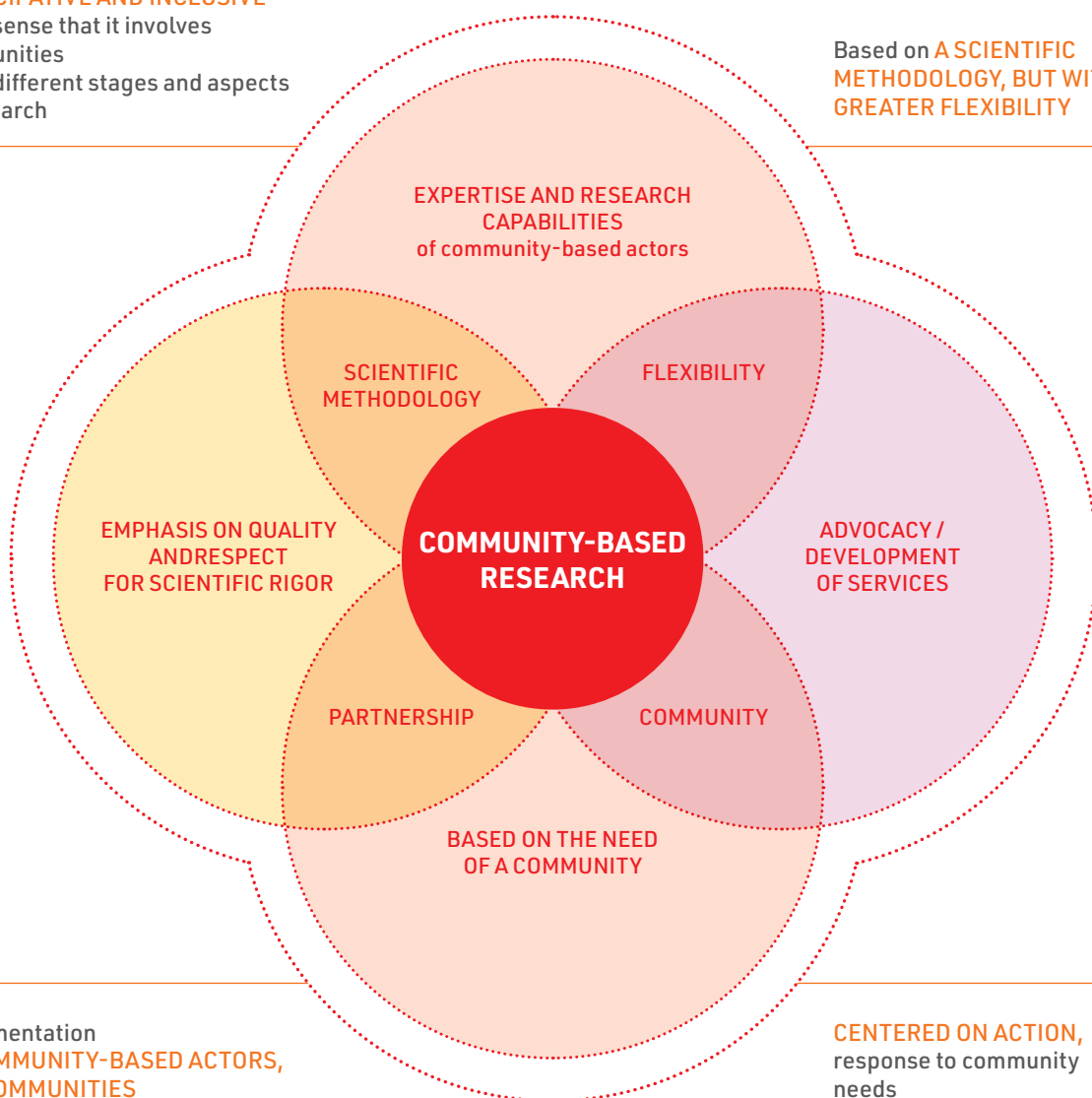
gor, which is **anchored in reality, uses a flexible methodology, is adapted to diverse contexts, is participative and inclusive, and is focused on action.**

## > WHAT IS COMMUNITY-BASED RESEARCH?

### PARTICIPATIVE AND INCLUSIVE

in the sense that it involves communities in the different stages and aspects of research

Based on **A SCIENTIFIC METHODOLOGY, BUT WITH GREATER FLEXIBILITY**



Implementation  
**BY COMMUNITY-BASED ACTORS,  
FOR COMMUNITIES**

**CENTERED ON ACTION,**  
response to community  
needs

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## EPIC according to the program stakeholders

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### EPIC IS A LEARNING PROCESS

For most community health workers and scientists involved in the program, EPIC is a “**learning and mutual reinforcement process**” with different opportunities for collaboration and consultation which strengthen the “**community**” cohesion of the program participants.

### EPIC: UNIFYING RESEARCH WITH SHARED AMBITIONS

Having **shared objectives** to achieve in different countries provides an opportunity for **comparative analysis** of the quantitative and qualitative data collected.

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### A PROGRAM THAT ALLOWS FOR...

- Collection and comparison/corroboration of data between the different participating countries, as part of a process of partnership and collaboration;
- Useful decision-making tools to implement and/or readjust public policies and strategies aimed at improving the living conditions of key populations;
- Advancement of national actions and thinking on task shifting, collaboration and complementarity between public and community-based health systems;
- Strengthening of Coalition PLUS intra- and inter-network collaboration as well as with other partners (public authorities, institutions, international organizations, etc.).



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# Program implementation

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## RESEARCH METHODOLOGY

The diversity of the epidemiological contexts in the countries that make up Coalition PLUS and the diversity of its organizations' human resources, technical and financial capabilities called for the construction of a program with a **flexible research methodology and management**. EPIC thus uses **mixed methods** to collect results (questionnaires and/or interviews), establishing a global yet detailed vision of the challenges associated with the health crisis.

DRIS provided the associations in the Coalition PLUS network with research tools (created and approved by the EPIC Working Group) such as: **a research protocol, questionnaires broken down into modules and interview guides, country and association information sheets** (activities and impact of the crisis on the association), **an operating charter, guidelines** for compliance with the GDPR (or equivalent depending on national regulations) and national ethics committee opinions. It also organized **training sessions on use of a data collection and analysis tool (VOXCO®)** to empower researchers and community actors within the participating organizations.

EPIC therefore forms part of a broader mission led by Coalition PLUS to **structure community research within the network through: (1) capacity-building; (2) development of new collaborations; (3) sharing of community-based expertise and knowledge.**

## GOVERNANCE AND OVERSIGHT

There are three levels to the program's shared governance:

- Joint Working Group (community health workers, academic researchers);
- Steering Committee per network and, for some associations, local steering committees and local scientific councils;
- Coalition PLUS Secretariat DRIS, for **overall coordination.**

# Achievements and levers of the EPIC program as perceived by its stakeholders

## MAIN ACHIEVEMENTS

The implementation of the EPIC program enabled **the community-based associations** : to **involve the community** in all steps of the research; to **raise their profile** among various target audiences; to identify the challenges and needs of key populations; to **strengthen the associations' linkages** with key populations; to publicize their services among people from key populations who were not already aware of them and to consequently **increase the number of potential beneficiaries**.

**Within the network**, the program strengthened team cohesion, the feeling of solidarity, mutual assistance and communication for the DRIS team and members of the Community Research Laboratory; **consolidated existing collaborations and created new links** between the associations and the academic researchers; and **strengthened** the community research and **community research project management capacities** of the associations thanks to the "learning by doing" approach.

→ **Support from the DRIS team:**  
technical assistance in the implementation of the EPIC program

→ **Training** (VOXCO® software, conducting a qualitative interview, qualitative and quantitative analysis techniques, producing an analysis plan, producing research questions, etc.)

### SUCCESS FACTORS AND LEVERS

→ Implementation of effective research tools

→ Implementation of effective management tools

→ Increased human and financial resources over the course of the program implementation



# Challenges and difficulties expressed by the program stakeholders

## COMPLEX PROJECT MANAGEMENT DUE TO:

- **The difference** in associations' **capacities to conduct research and reach vulnerable populations**;
- **The lack of human resources and/or research skills** of partner organizations (qualitative research) which called for considerable support from some network-lead associations;
- **The on-boarding of new personnel** within DRIS, which delayed some of the activities planned as part of the project;
- **Difficulties in obtaining funding.**

## THE COVID-19 HEALTH CRISIS AND THE MANIFOLD CRISES (POLITICAL, SOCIO-ECONOMIC, ETC.) IN OTHER COUNTRIES PARTICIPATING IN THE EPIC PROGRAM

- **Pressure on the research deadlines** in the rapidly changing context of the pandemic and the need to obtain results quickly in order to carry out advocacy actions;
- **Difficulties in attending face-to-face interviews** due to the restrictions connected with the COVID-19 health crisis;
- **The multiple crises**: in some countries, the series of crises (health, political, economic, etc.) delayed the project start and made it difficult to recruit participants for the research.

## DIFFICULTIES IN OBTAINING NATIONAL ETHICS COMMITTEE OPINIONS

- ...due to the restrictions imposed by COVID-19 and also because community-based research still has a long way to go to gain credibility in the academic world.

## DIFFICULTIES IN RECRUITING PROGRAM PARTICIPANTS

→ ...as some people from key populations were already in high demand from other research projects and, due to the cultural challenges and lack of trust in public policy, it was sometimes difficult to convince participants of the importance of this research.

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## DIFFICULTIES IN DIGITAL DATA COLLECTION

→ Working with **digital platforms from a research perspective was a first** for most of the teams involved in the EPIC program, and although they were particularly useful over the course of the program, **the associations' digital skills varied greatly**, which at times hindered their use.

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# Key lessons learned from the program implementation experience

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## LESSONS LEARNED WITH REGARD TO THE CHALLENGES OF COMMUNITY-BASED RESEARCH

**This project strengthened the feeling of belonging** of the community-based associations, members and partners to Coalition PLUS and to a civil society organizations social movement. **It produced vital scientific data and knowledge** to protect and improve the lives of and access to health services for key populations, anticipate actions to put in place in the context of the health crisis, and make the voice of “invisible” populations heard by policy decision-makers and public health systems.

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## LESSONS LEARNED WITH REGARD TO MANAGING THE RESEARCH PROGRAM

### → GLOBAL DYNAMIC:

**the participative and creative team work and the constant and effective communication with the Coalition PLUS organizations demonstrated** that in a context of a research project/program implementation, it is important to foster collaboration, sharing of experiences and inter-association learning.

### → THE PROGRAM MANAGEMENT FRAMEWORK

**and the importance of anticipating, of developing several scenarios for potential requests** for participation in order to identify problems (and solutions) in advance (notably workload); of **getting people from key populations more involved in community-based research**; of **effective internal communication**; of **attempting to keep other departments (Advocacy, Services) involved within the Secretariat and the associations** – despite the uncertainty regarding the potential program results.

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#### → THE RESEARCH PROGRAM PLANNING

**Allocating more time and human resources** to pre-testing the feasibility study among the target group and the understanding of the questions by those in the target group for the study; overcoming the challenges linked to **multilingualism**; drawing up an **initial planning** with the participating structures to ensure better co-construction; drawing up an **overall planning schedule** for the study.

Lastly, finding an **appropriate balance** between the **targets set** for a research project/program and **available resources**.

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#### → COORDINATION AND OVERSIGHT:

having a **full-time global coordinator, with an overall view of the project and who ensures follow-up** and liaisons in each of the Coalition PLUS networks; having an **optimum skills level** (knowledge and know-how) in team management and network coordination and **consultation** with the participating associations to jointly prepare the program management **procedures and regulations**; creating and updating **coordination and monitoring tools** without them becoming burdensome for the team; having a **shared communication tool** and encouraging **smooth operation** (budgets, administrative and financial procedures, communication, etc.).

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#### → BUILDING ASSOCIATIONS' RESEARCH CAPACITIES:

**organizing ongoing training in the field of community-based research**; planning inter-association and/or inter-network **experience-sharing sessions** to pool skills and good practices.

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## Comparative overview of success stories

### THREE SUCCESS STORIES WERE ANALYZED, BRINGING TO LIGHT CHALLENGES SPECIFIC TO EACH OF THE PARTNERS:

→ Lusophone network (8 countries): interest of consolidating connections and relationships with partners associations within the Network; conducting a comparative and synchronized analysis of the impact of the health crisis on key populations in the eight countries in the Network, geographically dispersed.

→ Fundación Huésped (Argentina): documenting the impact of the crisis on a single key population, women sex workers, through an advanced statistical analysis and a scientific publication.

→ BéSyP (Benin): building its capacities in terms of structuring and oversight of a community-based research project in order to initiate/lead this type of study autonomously in the future.

### BUT, TAKEN ACROSS THE BOARD, THE GAINS ARE AS FOLLOWS:

1

**Capacity-building for associations in research techniques and structuring and in research project management.**

2

**A network-strengthening impetus, at different levels:** between associations in the same network, with other community-based associations at regional level, at national level with specific associations.

Inter-network: exchanges between the Fundación Huésped and PILS in terms of recruiting trans people for the study.

**The key success factors common to the three experiences are the direct involvement of key populations in the recruitment of participants in the studies and empowerment, and capacity-building for community-based structures in conducting research in line with their own partnership goals or carrying out new activities.**

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## Conclusion

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The strength and key to success of community-based research remains a **balanced partnership** between community-based researchers, academics and other stakeholders, thus mobilizing a multitude of skills, expertise and professional and personal experiences.

EPIC demonstrated that the actors in the fight against AIDS know how to constantly **adapt** in order to listen and respond to those most vulnerable to these infections and make sure they have access to the health services and socio-economic support they need.

The results of the EPIC program capitalization process show that the health crisis was, for Coalition PLUS and its members and partners, a warning bell, but also an opportunity to do things **differently, better and together, with and for communities**.

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