

# Community and civil society engagement

**Without genuine community and civil society engagement, even the most well-intentioned health investments risk missing the mark – developing products that people won’t use, overlooking barriers that matter most, and leaving marginalized groups behind.**

History has shown that when programs are developed for communities rather than *with* them, uptake stalls, inequities widen, and the promise of innovation falls short. This clear evidence of what happens when lived experience is absent from decision-making underscores the urgency and value of Unitaid’s approach. Our 2023–2027 Strategy recognizes this explicitly, elevating community and civil society engagement as a core feature of how we work and one of the primary levers for achieving sustainable, equitable access.

Civil society and community engagement is a foundational pillar of our strategy to accelerate equitable access to health innovations and sustain health outcomes. This means ensuring

that communities and civil society partners are positioned as co-creators and implementers of durable solutions. Our goal is to ensure that the lived experiences, preferences, voice and agency of communities are integrated throughout our entire investment cycle – from identifying priorities and shaping program design, governance, and decision-making, to driving implementation, advocacy, and scale-up.

This goes beyond engagement; it is a quality-assurance mechanism, a platform for impact and ownership, and a strategic lever for policy reform and social transformation. By anchoring our work in community leadership and accountability, we strengthen not only the effectiveness of our investments but their lasting sustainability – ensuring that innovations endure, evolve and deliver impact for the long-term.

## How we work

At Unitaid, we save lives by making health innovations available and affordable for people in low- and middle-income countries. We identify innovative tests, treatments and tools, help tackle the market barriers that are holding them back and get them to the people who need them – fast.



Community centered strategies are critical to our ability to meet health outcomes and contribute to development goals. The following examples show how our programs position affected communities as the architects of health innovation.

### **Research with affected communities**

**at the heart:** The hepatitis C virus (HCV) disproportionately affects people who inject drugs, where stigma, weak health systems and limited harm reduction services have long restricted access to HCV prevention and treatment. Additionally, communities have historically been excluded from decision-making, leaving interventions poorly adapted to the lived realities of the people most impacted.

Our HCV programs have proactively addressed this imbalance. Together with our partners, we supported the creation of a community advisory board (CAB), embedded across program activities and empowered to guide research and implementation studies. Chaired by the International Network of People who Use Drugs (INPUD) and with representatives from all 10 study countries and two regional networks, the CAB has played a central role in shaping research

on harm reduction tools such as needles and syringes that reduce virus transmission, and long-acting depot buprenorphine used to treat opioid dependence. CAB members also ensure language is understandable, accessible and culturally competent, develop peer-led information resources and champion the importance of client choice in treatment programs.

Community researchers have also helped integrate lived/living experience. In each of the focal countries, they have led focus groups and key informant interviews, making the data collection itself community-led and owned. This approach has shifted accountability, embedding the principle of “nothing about us without us” into the heart of the HCV programs.

The impact has been tangible: research protocols were revised to reflect lived/living realities, recruitment tools became more accessible, and community education is improving demand for new interventions. At a structural level, the CAB’s influence has been recognized in national research protocols and ethics reviews.

This unique approach, which has built trust and strengthened the advocacy skills of networks of people who use drugs, is already inspiring similar approaches in other harm reduction and blood-borne virus research, demonstrating that inclusive governance can guide evidence generation and speed up access to health innovations for marginalized communities.

**Photo:** © Unitaaid



### Community health workers on the frontlines

**of access:** Health challenges in rural India are not always about whether hospitals or doctors exist; they are often about whether people know, trust and use them. For pregnant women, adolescents and tribal families, the barriers are much deeper: stigma, cultural taboos and lack of information often come in the way of safe healthcare choices.

Together with our partners Jhpiego, Pahal and other community-based organizations, we've been working in Maharashtra and Madhya Pradesh. In many tribal belts of these states, 40-50% of births still happen at home, compared to a national average of 12%. Long distances, poor transport and traditions keep families away from health facilities.

That's where community-based organizations come in. Local organizations are trusted by their communities and have become a bridge between families and health systems, using awareness drives, household counselling and learning activities to start conversations on antenatal care, safe birth practices and postpartum hemorrhage, among others - ensuring maternal health is a collective priority, not solely a women's issue.

In many of these remote communities, women have to travel several hours to reach their nearest hospital, and some do not make it in time. That's why the program strategy is two-fold: promote institutional deliveries as the first choice, while equipping families with emergency knowledge, practices and prevention tools - like misoprostol, which can prevent life-threatening bleeding after birth - when hospitals are out of reach.

In the four program districts, institutional delivery rates are rising, and awareness is growing. Close to 40% of women who would have previously given birth at home made it to the hospital for their deliveries.

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**Families no longer see health advice as an order—they see it as a shared learning. This trust has made them more open to safe, institutional deliveries.**

**Subham, Program Manager at Pahal,**  
a community-based organization that works  
with tribal communities to increase knowledge,  
understanding and uptake of health interventions.

Community health workers have also been instrumental in expanding access to tuberculosis (TB) preventive treatment, particularly in remote and underserved areas. In Sierra Leone, we work with the civil society organization CISMAT to support these workers in identifying people at risk of TB infection and connecting them to timely preventive treatment and care.

In addition to delivering medical support, they combat stigma and misinformation, helping communities understand that TB is both preventable and curable. These early interventions protect the most vulnerable - especially children and pregnant women - while reducing transmission within families and the wider community.

### Designing programs around the needs of those most at risk:

HIV, syphilis, hepatitis B and Chagas disease affect pregnant women and cause more than one million cases of preventable illness, disability or death among newborns per year. Marginalized groups, especially adolescents and women with limited access to care, are among those most impacted.

Simple diagnostic tests and affordable treatments that can stop transmission already exist but do not reach populations in need due to a range of challenges. Together with our partners including PATH, the International Community of Women living with HIV Eastern Africa and the World Hepatitis Alliance, we are working across 19 countries to accelerate demand and adoption of evidence-based approaches and integrated delivery strategies to ensure pregnant women get the care they need and ensure their babies have a healthy start in life.

Prioritizing lived experience, we are working with our community partners to reduce stigma, support women to get themselves and their partners tested and treated, increase demand and acceptability of products and reinforce antenatal services at lower levels of the health system to reach more women where they are.

Together, these efforts are strengthening the foundation of antenatal care – ensuring services are more welcoming, more integrated and better aligned with what women say they need.



**An integrated approach to service delivery is ensuring that everyone is on board — from communities, people living with HIV and other diseases, civil society, political leaders, non-governmental organizations, and government representatives — all at one table discussing issues that affect service users.**

**Immaculate Owomugisha,**  
Centre for Women Justice Uganda

### Our commitment

Over our 20-year history we have worked alongside affected communities to transform care for HIV, TB and malaria, ensuring all populations – children, pregnant women, marginalized groups and others – can access the highest quality care available. Through these experiences, we have learned that early engagement creates responsive programs. The combined power of community voices with civil society action can quickly drive-up demand and raise awareness among affected communities, which in turn accelerates the scale up of innovations in global health.

Our commitment to equity is not just a principle – it is practice demonstrated by the representation of communities and civil society on our governance and accountability structures, ensuring that partners assist in steering our organization and shaping solutions.

### About Unitaid:

We save lives by making new health products available and affordable for people in low- and middle-income countries. We work with partners to identify innovative treatments, tests and tools, help tackle the market barriers that are holding them back, and get them to the people who need them most – fast. Since we were created in 2006, we have unlocked access to more than 100 groundbreaking health products to help address the world's biggest health challenges, including HIV, TB, and malaria; women's and children's health; and pandemic prevention, preparedness and response. Every year, more than 300 million people benefit from the products we've helped roll out.

