

# Community cancer watchers: The experience of the Union of People Affected by Texaco's Oil Operations (UDAPT) in the Ecuadorian Amazon

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Since the 1970s, the northern Ecuadorian Amazon has been the site of intense and prolonged oil exploitation that has generated profound environmental, social, and health consequences. Extractive activities, characterized by recurrent oil spills, unremediated waste pits, and the continuous flaring of gas, have led to persistent contamination of water, soil, and air. For example, Texaco (now Chevron) operated in the Ecuadorian Amazon between 1964 and 1992, leaving behind more than 880 open toxic waste pits and discharging approximately 60–64 million liters of toxic wastewater. These impacts have accumulated over more than five decades, disproportionately affecting rural and Indigenous communities that depend fundamentally on their territories for subsistence, cultural identity, and community life [1–3].

Numerous testimonies and local evidence have pointed to an increase in serious illnesses, premature deaths, and chronic conditions, many of them lacking timely diagnosis and adequate access to treatment [4–5]. Despite the magnitude of the damage, the response of the Ecuadorian state has been insufficient, failing to fully recognize the structural causes of this crisis or to develop effective policies for environmental and health remediation. In this context of persistent contamination, institutional neglect, and systematic violations of rights, community responses have emerged, such as the Union of People Affected by Texaco's Oil Operations (UDAPT), aimed at protecting the lives and health of populations affected by territorial contamination.

## The UDAPT community cancer surveillance system

UDAPT is a non-profit Ecuadorian organization created in 1993 that brings together Indigenous and rural communities of the Amazon (mainly from the provinces of Sucumbíos and Orellana). Its purpose is to demand comprehensive reparation for the damages caused by Chevron–Texaco's oil operations and to defend human rights and the rights of nature in the face of extractive industries [6].

UDAPT's community cancer surveillance system (CCSS) emerged as part of this struggle and represents a collective response to the social, environmental, and health injustices caused by oil exploitation in the northern Ecuadorian Amazon. The initiative to create this surveillance system arose when community leaders from different nationalities began to identify alarming patterns of illness and deaths with no apparent cause, along with the absence of timely diagnoses and adequate treatment in their communities. As will be described later, the system operates through a network of community volunteers who identify suspected cancer cases, contribute to their confirmation, and provide accompaniment through close follow-up.

The CCSS thus represents not only a health care strategy but also a space of political and social struggle that advocates for a comprehensive understanding of health, inseparable from the environmental, social, and cultural conditions of the territory under surveillance.

Community organization and structure of the system The foundations of UDAPT are made up of people who have directly experienced the impacts of oil contamination: long-standing community activists, plaintiffs, community monitors, and families affected by illness, violence, discrimination, and persecution. The surveillance system is grounded in principles of grassroots leadership, horizontality, and shared responsibility, avoiding rigid hierarchical structures.

Its functioning is closely linked to the so-called "reparation committees", which constitute the territorial core of the organization. These committees are composed of members of the communities themselves (community leaders, people with cancer, family members, and other local actors), and act as focal points for coordinating the different areas of organizational work.

Each community has a reparation committee composed of around five members who coordinate actions related to health and cancer projects, safe water, soil

recovery, and cultural revitalization. This structure allows for the early identification of health problems and the activation of timely responses in collaboration with a multidisciplinary team, based on the understanding that health cannot be addressed in isolation from environmental contamination or from the multiple forms of structural violence present in the territory, including gender-based violence.

### The community surveillance team and its functioning

The community cancer surveillance system (CCSS) is sustained by a small team that is deeply rooted in the communities. It is composed of nineteen women (community health promoters) who form the operational core of the project and carry out their work with a strong human, community, and political commitment.

The health promoters play a central role in the functioning of the system. They conduct home visits to identify cases and verify diagnoses issued by health centers or hospitals, provide alternative therapies, accompany cancer patients, and offer basic nursing assistance. They also manage referrals and medical appointments both within and outside the Amazonian territory, particularly in the city of Quito. This organizational network allows the project to function as a community-based early warning system for cancer cases.

Project leadership is exercised from the community level and is structured around a General Health Coordination, led by a nursing technician, a cancer survivor herself, and member of the surveillance system since its inception. This coordination is supported by a medical sub-coordination and by cantonal focal points located in Coca, Lago Agrio, Sacha, and Shushufindi, who coordinate territorial work with the team of volunteer health promoters. These promoters receive a small financial compensation for the services they provide.

The entire team maintains ongoing coordination with the reparation committees of rural and Indigenous communities in the provinces of Sucumbíos and Orellana.

The activities of the CCSS combine direct support for patients and families with community-based research and political advocacy (Image 1). A central component has been the identification and systematic registration of cancer cases in the Amazon region, which has enabled the creation of the Biprovincial Tumor Registry of Sucumbíos and Orellana since 2018. This registry constitutes a key tool for making visible the magnitude of the cancer burden in the territory and for demanding institutional responses from the Ecuadorian state.



**Image 1.** Home visits to patients' homes to collect information and assess their needs.

The data collected so far (611 registered cancer cases) reveal serious limitations in access to timely diagnosis and treatment. All affected individuals must travel to the capital city, Quito, or to other cities to receive specialized care. This requirement significantly restricts effective access to health services, increases the economic and social costs for patients and their families, and raises the risk of death.

Moreover, many people die without ever receiving a diagnosis or accessing oncological care, in a context marked by the absence of systematic state-led investigations that could clarify the causes and extent of this situation.

The process has also generated concrete outcomes. At the institutional level, collaborations have been established with some entities within the public health system, facilitating timely referrals, particularly in cases of cervical cancer. In addition, training processes have been developed for local health personnel, and the first theoretical and practical course on early detection of breast cancer in the Amazon has been implemented.

In the legal arena, UDAPT has promoted judicial actions in response to violations of rights, obtaining favorable rulings. These include a court order mandating the creation of an Oncology Unit in the province of Sucumbíos, whose implementation remains pending [7,8].

The CCSS adopts a comprehensive care approach that integrates Western medicine with ancestral medicine and alternative therapies, such as biomagnetism, reflexology, moxibustion, auriculotherapy, and therapeutic massage. This approach seeks not only to alleviate physical symptoms but also to support the emotional, social, and spiritual well-being of people living with cancer, as well as to accompany their families, particularly in palliative care contexts where institutional support is often absent (Image 2).



**Image 2.** Capacity-building workshop on breast cancer prevention involving patients, family members and committee members.

### Dissemination of activities

The CCSS provides information to UDAPT, which in turn disseminates its work through an integrated strategy that combines community communication, systematic documentation (physical, digital, and audiovisual), and political advocacy actions. Information is continuously shared with direct beneficiaries and with the reparation committees, ensuring that communities remain informed about the research findings and the actions undertaken.

In addition, we publish the Biprovincial Tumor Registry Bulletin annually. This bulletin is presented to public health authorities as a tool to make visible the magnitude of cancer in the region and the urgent need to strengthen oncological care, including improved access to specialized services and the creation of an oncology hospital in the Amazon. Complementarily, the organization uses its institutional communication channels and establishes partnerships with independent media outlets to raise awareness about the Amazonian health crisis, the impact of environmental contamination on health, and the longstanding demands of affected communities.

### Funding and sustainability

The financing of the system comes primarily from international solidarity, particularly from organizations based in Switzerland. This external dependence paradoxically reflects the lack of engagement of the Ecuadorian state in addressing the health crisis in the Amazon. Despite being territories that have historically generated wealth for the country, the provinces of Sucumbíos and Orellana continue to face structural poverty, persistent environmental contamination, and limited access to resources, which threatens the long-term sustainability of the community health system.

### What we have learned

Over the years, the CCSS has learned that solidarity, collective work, and accompaniment are central components of health care. Medical care, when available, is not always sufficient or accessible. In particular, people requiring palliative care are often neglected by health institutions, generating profound suffering not only for patients but also for their families.

In response to this reality, emotional and spiritual support, together with complementary therapies promoted by the CCSS, have proven essential for sustaining dignity, hope, and continuity of care in contexts of institutional abandonment such as ours.

The work of the community surveillance system has also revealed that the health system in the Amazon is severely weakened. Delays in cancer diagnosis and treatment persist, there is no oncology hospital in the region, and the availability of specialists is extremely limited. Psychological support for patients and their families—an essential component of cancer care—remains inadequate. This situation is compounded by the precarious nature of private health services, where in some cases the vulnerability of patients is exploited, as well as by the political instrumentalization of the suffering of people with cancer through electoral promises that remain unfulfilled. All of this occurs in a context of persistent environmental contamination, often obscured by narratives of economic progress despite its association with multiple health impacts.

### Our challenges

Looking ahead, the community surveillance system faces several key challenges. These include strengthening community organization and awareness for the active defense of the rights to health, social justice, and environmental justice; improving the collection of information on cancer cases as a tool for demanding accountability from the state; and ensuring the creation and effective operation of an Oncology Unit in the region, with sufficient and sustained funding that transcends changes in government.

It is also essential to promote profound transformations in public policies related to health, social justice, and environmental justice, including the effective implementation of judicial rulings linked to the Special Amazon Territorial Circumscription (CTEA), a state body created to guarantee integrated planning, sustainable development, environmental protection, and Buen Vivir for Amazonian populations.

Finally, it is crucial to move toward comprehensive reparation that explicitly recognizes the causal relationship between environmental contamination and health impacts, particularly cancer incidence, in the Ecuadorian Amazon.

## DECLARATIONS

### Competing interests

MJC is an active member of UDAPT.

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None.

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