

Civil Society Trends and Patient Advocacy in Latin America

To empower patients to advocate for themselves in all parts of the cancer journey with the ultimate goal of improving health care and creating a patient focused approach to prevention, detection, treatment, end of life and survivorship.

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ACS Assessment of Civil Society Development in Latin America

- Market analysis (70 NGOs from 11 countries)
- Institutional analysis of key drivers of NGO effectiveness: governance, fundraising, community involvement, patient services, media strategies and survivorship/volunteerism
- Identified strengths and weaknesses to develop NGO capacity building projects to address weaknesses



Overall Findings Related to Cancer NGO Sector in Latin America

- In most markets the NGO sector breaks down into four groups: non-site specific cancer, breast cancer, children's cancers and non-tumor cancers.
- In most cases the breast and pediatric cancer groups are the most vocal
- Not enough survivorship for real advocacy movement



Obstacles to Civil Society in Latin America

- The culture of silence around cancer
- The lack of a cancer community-networks
- No “face” of cancer-survivors
- A rigid hierarchy of the doctor-patient relationship that is particularly pronounced in the region
- Weak political systems that produce ineffectual public health systems
- Weak NGO organizational development



The American Cancer Society: Lessons in Civil Society and Cancer Control

What we know:

Information...

Creates consumer demand...

Which drives political will



Civil Society Responsibility is to:

- Create systems to inform citizens, patients and family members
- Raise visibility of survivor to give hope and generate popular demand
- Use volunteer and survivor base to affect change on the policy level





Interventions to Accelerate the Patient Advocacy Continuum

- Enhanced patient information vehicles
- Tools to connect survivors
- Involving NGOs and survivors in national cancer plans
- Development of networks
- Creation of trained and qualified civil society actors

Vision

To strengthen civil society in cancer control in Latin America.

Objectives

- Increase NGO's organizational capacity
- Strengthen the NGOs' programmatic capacity – leverage early detection
- Increase the NGOs' reach into the survivor and volunteer communities
- Strengthen NGO and survivor networks to support advocacy efforts




Objective 1:

Increase NGO's organizational capacity


- 1) Cancer Control and Program Development and Evaluation
- 2) Strategic Planning and Volunteer Recruitment
- 3) Patient Advocacy and Communications
- 4) Policy Impact.

ACS will also provide institutional assessment and customized technical assistance plan



Objective 2: Strengthen the NGOs' programmatic capacity – leverage early detection

1. Early detection key to stage shifting
2. Grants for early detection projects
3. Ongoing technical assistance and support



Objective 3: Increase the NGOs' reach into the survivor and volunteer communities

1. Requirement of grant proposals
2. Requirement of entrance to program
3. Training and support in volunteer recruitment, training and retention



Objective 4: Strengthen NGO and survivor networks to support advocacy efforts

1. Support in policy analysis
2. Training in advocacy
3. Technical support in system change
4. Networking support to create survivor network for advocacy

