

**A MODEL INTERVENTION FOR
EARLY DETECTION AND PREVENTION
OF **CERVICAL CANCER**:
AN INNOVATIVE PARTNERSHIP IN ROMANIA**

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Acronyms and Abbreviations

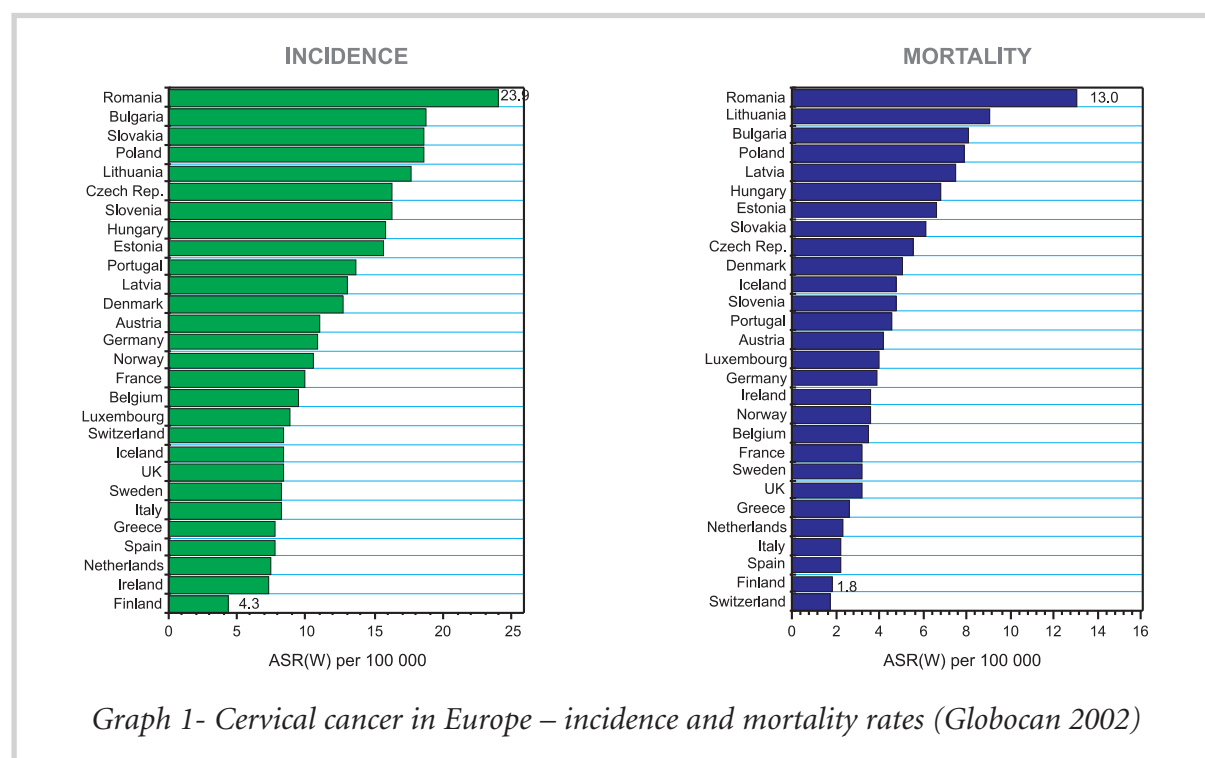
GP	general practitioner
IOCN	Cluj – Napoca “I. Chiricuta” Institute of Oncology
JSI R&T	JSI Research & Training Institute, Inc.
NGO	nongovernmental organization
Pap	Papanicolaou
PSI	Population Services International
RFHI	Romanian Family Health Initiative
RRHS	Romania Reproductive Health Survey
SRC	Romanian Cancer Society
USAID	United States Agency for International Development

I. BACKGROUND

Cervical cancer is a major worldwide public health problem. Its incidence places it second to breast cancer among the female neoplasia and sixth among the major types of cancer on a global scale.

This type of cancer represents a principal area of action and research within the public health field, as the disease can be prevented by employing a simple exam of cervical-vaginal cytology or the Papanicolaou (Pap) smear. The cervical-vaginal smear is one of the most efficient screening tests available in oncology, acknowledged for its major contribution to a marked decline in global cervical cancer incidence and mortality.

Cervical cancer incidence and mortality disparities across geographical regions reveal both differences in screening program implementation and variations in major risk factors including socio-economic standards, social class, and sexual behaviors.



Cervical Cancer in Romania

Romania has the highest incidence and mortality rates in Europe, a situation that has been constant since the early 1980s.

In Romania in 2006, 1,839 women died and more than 3,000 new cases were diagnosed, making cervical cancer second to breast cancer among the female neoplasia. According to estimated data for 2000 of the International Agency for Cancer Research, one woman in 44 was at risk of cervical cancer, almost eight times higher than the risk in Finland, for example.

Cervical cancer particularly affects young, active women, representing the primary cause of death for the Romanian female population aged 20–44 years old. This correlates with recent increases in incidence, highest in younger women. This pattern is similar to that in developed countries and is primarily due to changes in sexual behavior, as well as an increase in smoking among women.

Because the disease disproportionately affects young women, over 30,000 life years are lost annually in Romania due to premature deaths caused by cervical cancer.¹

This situation reflects both changes in risk behaviors and the inefficiency of the cancer prevention measures adopted in the past. In spite of the well-known benefits of the Pap smear test, a very small number of women in Romania are tested annually, largely through opportunistic screening during a regular gynecologic examination. Only 3.4 percent of the female population in Romania was tested in 2003, compared to the European standard for efficient screening of 85 percent coverage.

The population's low levels of knowledge and awareness regarding cervical cancer also contribute to current incidence and mortality. According to the 2004 Romania Reproductive Health Survey (RRHS), "more than 80 percent of sexually experienced women have never had a Pap smear test for cervical cancer and 37 percent say they have never heard of the test. Only one of six women reports that she was screened for cervical cancer during the three years preceding the survey". The situation is particularly difficult in rural areas, where "nine out of ten women have either never heard of the Pap test or have heard of but never had the test".

The situation in Romania requires interventions designed specifically to reach the most vulnerable women. The 2004 RRHS reports that 89 percent of rural women, 91 percent of women who completed only elementary or lower secondary school, and 93 percent of women in the lowest socio-economic category had never been tested². Although there is no coherent national screening program in place, initiatives at the local level address this important problem.

This paper describes efforts to improve the early detection and prevention of cervical cancer in four districts in northwestern Romania. The "I. Chiricuta" Institute of Oncology in Cluj-Napoca (IOCN) and the Romanian Cancer Society (SRC) initiated interventions in 1999. In 2003, the program became part of the Romanian Family Health Initiative (RFHI), a partnership coordinated by JSI Research & Training Institute, Inc. (JSI R&T) and funded by the United States Agency for International Development (USAID).

¹ Romanian cancer data are from the Centrul Național pentru Organizarea și Asigurarea Sistemului Informațional și Informatic în Domeniul Sănătății.

² 2004 Reproductive Health Survey Romania, Summary Report, May 2005, page 58.

II. EARLY DETECTION AND PREVENTION OF CERVICAL CANCER: A MODEL INTERVENTION

RFHI began in 2001 with the aim of expanding access to reproductive health services, especially for the underserved. The project strategy was to strengthen primary care, thus ensuring maximum coverage. Although RFHI's main focus was family planning, it also addressed other areas of reproductive health, such as HIV and AIDS prevention, safe motherhood, domestic violence, and early detection of breast and cervical cancer. Within this broad framework, the program for early detection and prevention of cervical cancer in Cluj district began in October 2003. It represented RFHI's response to unmet needs of disadvantaged populations, through the continuation of activities previously implemented by the SRC and IOCN with funds provided by the Ministry of Public Health or donors.

From 2003–2006, the program had four components, each of them representing both improvements in and geographic expansion of previous interventions:

- Prevention and early detection of breast and cervical cancer for underprivileged women in Cluj district. (October 2003–January 2004)
- Prevention and early detection of breast and cervical cancer for underprivileged women in Cluj and Sălaj districts. (February 2004–January 2005)
- Model for early breast and cervical cancer detection in Cluj, Sălaj, and Satu Mare districts. (February 2005–January 2006)
- Model for early breast and cervical cancer detection in Cluj, Sălaj, Satu Mare, and Bistrița-Năsăud districts. (February 2006–September 2006)

SRC and IOCN carried out the implementation, building on their previous work. IOCN ensured co-financing, including the endowment of the medical van used by SRC for performing Pap smears. IOCN also treated patients with dysplasia and cancer and maintained the management information system.

Partners

Critical to the success of the program was the innovative partnership established between public- and private-sector actors. What began in 2003 as a collaboration between IOCN and SRC, grew into a broad-based network that included both public institutions and nongovernmental organizations (NGOs).

Leadership Partners

The Romanian Cancer Society (SRC)
 “I. Chiricuță” Institute of Oncology in Cluj-Napoca (IOCN)

Public Partners

- Cluj-Napoca University of Medicine;
- District public health authorities (Cluj, Sălaj, Satu Mare, Bistrița-Năsăud)
- Cluj District Health Insurance House
- Cluj prefecture and all local municipalities

Nongovernmental Organizations

- Romanian Society of Oncology Surgery
- Romanian Association of Health Psychology
- Population Services International (PSI)/Romania
- Cluj Napoca Center for Health Services

The leading partner, **the Romanian Cancer Society (SRC)**, an NGO with many years of experience, had the overall responsibility for program implementation and results. In order to reach out to disadvantaged populations, SRC used a well-equipped van, procured under a previous program implemented by the organization. SRC also facilitated the collaboration among the various partners.

“I. Chiricuță” Institute of Oncology (IOCN), one of the major scientific bodies in oncology in Romania and the center of reference for the Transylvania Region, was in charge of the medical component of the program. This included testing and lab cytology activities, as well as treatment of patients, when necessary. IOCN was also responsible for organizing the screening program registry thus ensuring the quality of the medical services performed.

Local authorities

During implementation, the program enjoyed the support of the local authorities. The team held regular meetings with public health authorities from the districts of Cluj, Sălaj, Bistrița-Năsăud, and Satu Mare, to inform, raise awareness, and advocate for the involvement of local general practitioners (GPs) and media in the program.

Important members of the community joined local initiative groups, which facilitated access to and mobilization of the target population. The efforts and commitment of the local groups led to increased impact of the information-education messages.

The involvement of local authorities and decision makers in rural areas directly contributed to program success, especially considering the fact that currently there is no legislation in Romania to stimulate participation in screening programs.

General Practitioners (GPs)

GPs played an important role in the project. Initially, the GPs were involved in the information-education activities, mobilizing women for the Pap test, communicating cytology results to patients and, depending on the case, in the follow up of women whose test results were abnormal. As the program evolved, it became clear that a more important involvement of the GPs was necessary, not only in informing and mobilizing women, but also in smear-taking activities. As a consequence, 101 GPs from Cluj and Satu Mare districts participated in theoretical and practical training courses. Although only some of them are providing complete services, including Pap smear-taking when test kits are available, their prevention skills have improved significantly, especially monitoring patients and referral to follow-up centers.

Beneficiaries

The project focused on geographically isolated women living in rural communities with difficult access to information and health services. It also sought to reach underprivileged urban women in need of services.

According to Romanian legislation, all women enrolled in the social health insurance system can receive a free Pap test every five years. However, as the results of the 2004 RRHS showed, access to these services is very limited, especially for rural women, due to both lack of physical access to services as well as specific information.

Strategic approach

Once the team identified difficulty in accessing services as the main barrier to the target group, the program strategy was to bring services to the population in need. This meant designing an outreach intervention model implemented by program professionals, but strongly supported by local stakeholders and the involvement of community family doctors. The roles and responsibilities of each partner were clearly defined and the contribution of the local community added tremendous value to the program.

Main activities

1. Information, education, and mobilization of the target population

The community GPs carried out this activity once they were informed about program objectives and planned activities. Information-education meetings were organized with groups of women between 20 and 65 years of age. The objective of the meetings was to raise women's awareness about the importance of breast and cervical cancer prevention and to inform them about Pap testing and breast self-examination. Educators distributed informational materials during the meetings. In addition to the group information sessions, each woman coming for testing benefited from individual counseling.

In addition to community-based activities, educators also organized information-education sessions in rural and urban schools. This was an efficient way to improve the knowledge of young people about breast and cervical cancer prevention, with the objective of changing attitudes about personal health, focusing on preventive behavior.

The GPs' involvement in the information and mobilization activities represented a major contribution and proved that the GPs can and should play a more important role in prevention initiatives in their communities. In future, this can be organized more formally, with the support of local decision makers and within a legal and policy context that would stimulate participation.

Towards this goal, the pilot program advocated for an increased role of local representatives in activities carried out within their community through the establishment of local initiative groups. These included the mayor, the GP, the school principal, and the priest: people who are influential with the target group. Their participation facilitated contact with the population, leading to more efficient implementation of prevention interventions. At the same time, the involvement of local stakeholders increased their awareness about problems in their communities and the need to find solutions to sensitive issues such as the great need for improved services for the uninsured.

Program experience underscored the value of engaging both the GPs and community members, as the involvement of the initiative groups is critical to achieving the local independence necessary to address future community problems.

Priests played a special role within the rural initiative groups, due to their credibility. The program sought support at the bishopric level and the bishops gave their approval. As a consequence, priests often transmitted “a Message for Women” in churches, highlighting the importance of breast and cervical cancer prevention activities.

Women also received information through posters or leaflets mailed to them specifying the date and place where testing would be organized. In some communities, local TV stations carried mobilization messages and contributed significantly to program participation.

The project demonstrated that good collaboration with the authorities and other local leaders leads to good mobilization of the target population for a successful screening program in rural communities. Moreover, the existence of local partnerships ensures the sustainability of such interventions in the future.

2. Provision of free Pap tests and mammograms

In order to organize the testing activities, the GPs from the program communities were informed and prepared to mobilize the women and schedule them for testing.

In communities without an adequate medical consulting room, the village authorities ensured a place where the mobile unit could camp and function.

The van, owned and administered by SRC, was specially equipped for providing gynecological examinations and Pap testing. The mobile unit went to the villages and the communes of the four project districts: Cluj, Sălaj, Satu Mare, and Bistrița-Năsăud. The Pap test and the breast examination were mainly performed by gynecologists, employees of the Institute, but also by trained GPs. If needed, the physicians provided women with free mammograms, the costs of which were covered by the program. Patients suspected of having malignant tumors had free access to treatment.



The GPs played a critical role in the smear-taking activity as their close relationship with their patients encouraged the women’s participation. In order to facilitate the involvement of the GPs, the SRC and the Association of Health Psychology in Romania together issued special materials that they either distributed to the GPs directly at training courses and monthly meetings, or by mail. Raising awareness of the local leaders was important, but also raising the awareness of the GPs of the importance of their role in the screening interventions was a key determinant of the program’s success.

The management information system is very important within a cervical cancer early detection and prevention program. IOCN designed and coordinated a comprehensive information system capable of ensuring the timely communication of results to the patient by directly involving the GP. The Cytology Laboratory of the Institute analyzed the tests, and results were sent to the GPs, who in turn communicated results to their patients. In this way, the program ensured that clients received test results at their local health facility, with few or no travel costs involved, while at the same time observing confidentiality protocols. Also, this system facilitated follow-up in the case of positive results and improved patient compliance with treatment.

3. Training and collaborating with the GPs to implement the screening program

IOCN and the Center for Health Services in Cluj-Napoca formed a partnership to implement the theoretical and practical training courses for a total of 101 GPs, working both in rural (54 GPs) and urban (47 GPs) areas in Cluj and Satu Mare districts. Some of the GPs had attended previous trainings on cervical cancer prevention.

The Romanian College of Physicians accredited the eight-hour theoretical course “Early Detection of Breast and Cervical Cancer: Clinical Interventions for Female Oncological Pathology Within Primary Health Care”. RFHI developed a curriculum that can be used for future trainings organized in other programs. The curriculum is available at www.jsi.com.

After the theoretical training, the GPs signed agreements with the IOCN, including either mobilization or testing of the population, or both. The gynecologist who accompanied the van supervised the smear-taking activity performed by the GPs. If the GPs succeeded in doing ten successive correct Pap tests confirmed as valid by the cytology laboratory, they were accredited to perform future smear-taking activities. Thirty-two GPs qualified and are now involved in smear-taking and breast examination activities, counseling patients to follow treatment, and reporting results in order to centralize them in the Cancer Registry. Patient counseling is carried out in partnership with the Romanian Health Psychology Association.

4. Reaching consensus in the professional community

The program held a conference to facilitate consensus-building among key stakeholders, including over 90 gynecologists, oncologists, cytologists, and GPs involved in the national prevention program. The objective was to establish a common framework of the standards and criteria that needed to be used, in accordance with European Union requirements and standards. Key conference outputs were a guideline to help the GPs in their outreach activities and the adoption of guidelines for cervical cancer early diagnosis and treatment that comply with European standards.

5. Sharing experience and disseminating results

In July 2006, the IOCN sponsored a dissemination conference in Cluj-Napoca to share information and experience gained during program implementation with national stakeholders and colleagues from all over the country. It was an opportunity for the professionals involved in cervical cancer prevention, early detection, and/or treatment to learn more about the innovative approaches and what makes a screening program successful, especially when working with disadvantaged groups. Discussion also focused on challenges and lessons learned.



The program disseminated results to international audiences as well. The poster “Model Intervention for Cervical Cancer Prevention: An Innovative Partnership in Romania” was presented at the 2007 Global Health Council Conference in Washington, D.C., and generated great interest.



Achievements

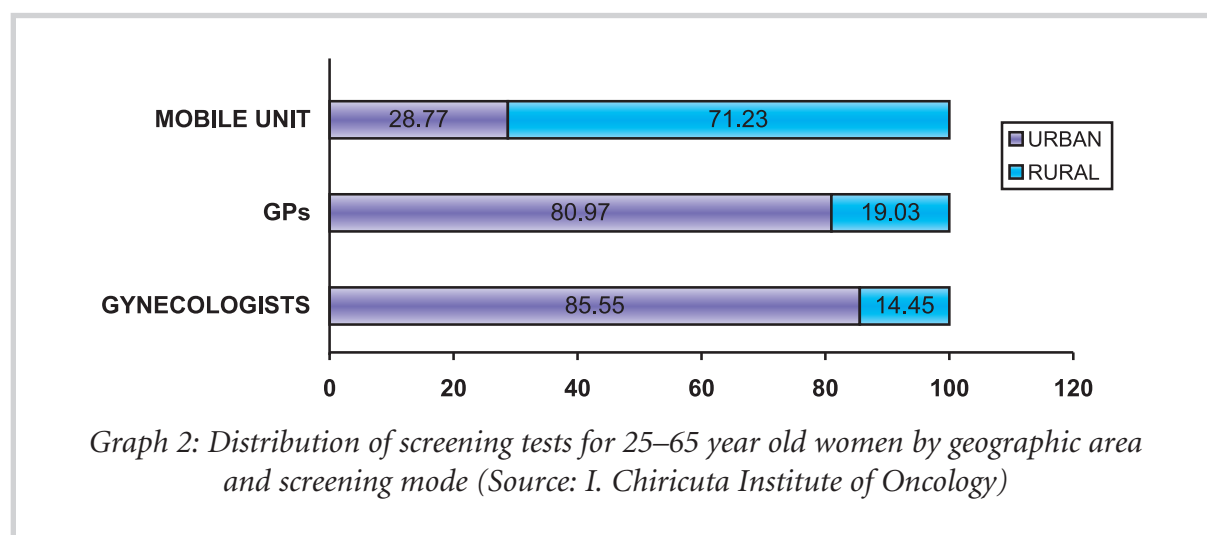
The program reached 116 villages and nine cities in the four districts in northwestern Romania. Educators conducted 209 group information-education sessions for 9,015 beneficiaries. They also provided individual information and counseling to the clients, both when conducting testing and communicating results.

A total of 13,402 women obtained Pap tests, of which **91 percent received the test for the first time in their lives**. In 5.24 percent of the tests, results indicated dysplasia and patients were included in the next phase of the screening program.

Clinicians conducted breast exams on 83 percent of the women and performed 260 mammographies for cases that needed further investigation.

The program trained 101 family doctors in prevention and early detection of cervical cancer. Of these, 32 received accreditation to perform Pap tests and 59 GPs became involved in information, education, and communication activities targeting women in their communities.

In comparing the activity of the three types of providers that were active during the cervical cancer screening program implemented in the four districts between 2002 and 2006—gynecologists, GPs, and the mobile unit—it is significant that although the mobile unit represented only 16 percent of the total screening activities, the majority of its work was in rural areas of greatest need.



This underscores the fact that the activity of the usual screening providers is very limited in rural areas as well as the need to use alternative outreach interventions. It also points to the need for training and involving rural family doctors as much as possible, as they are closest to the communities in greatest need.

Another important result of the program was the awareness raising of community stakeholders with respect to the cervical cancer problem and the mobilization of local initiative groups. In terms of sustainability, this might represent one of the most important program achievements.

The partnership created between public institutions and civil society also represents an important outcome of the program, in a country where examples of successful collaborations between the two sectors are scarce.

On the policy level, the program disseminated and shared the model with national and local decision makers who recognized it as a best practice in the field of cervical cancer prevention in Romania. This created not only a framework for policy discussions, but also the basis for

replication in other parts of the country. One of the most important policy and advocacy results of the program was the fact that the Ministry of Public Health increased the budget allocated to the IOCN for cervical cancer screening, thereby acknowledging its efforts in the area of public health. This will allow the Institute to continue its important work and encourage others to become involved.

Challenges and Lessons Learned

• Policy environment

Although Romania has the poorest cervical cancer incidence and mortality indicators in Europe, there is no coherent national policy in place to support early detection and prevention practices. The results of the 2004 RRHS reconfirmed the unmet need for prevention services within the Romanian population and identified the groups that are most vulnerable, with least access to services, and limited awareness of the cervical cancer problem.

The very few local programs, generally funded by donors, are limited and cannot meet the tremendous need for services, especially in vulnerable groups. In order to make a difference, these isolated interventions should be supported, and extended, by the public health sector. To achieve this, it is important to share service provision results and advocate with the most appropriate stakeholders. Although the program did not change the national policy, it managed to influence key decisionmakers to consider this national need and to try to improve the situation. This is a solid achievement for a locally driven program.

• Legislative barriers affecting the family doctors' involvement

Current legislation does not encourage GPs to participate in cervical cancer screening. GPs typically serve a large number of clients, do field work, visit their patients, and cope with a heavy administrative load. The Health Insurance House does not pay for cervical cancer screening services; therefore there is no incentive for the family doctors to provide these services, except for their own professional standards.

• Lack of partnership culture

In Romania, partnerships—especially those between governmental bodies and civil society—are difficult to create and maintain. Nevertheless, program experience proved that a strong motivation such as improving people's lives can overcome partnership obstacles. A key lesson is that each of the parties involved must agree to a clear description of its roles and responsibilities, covering either the medical, social, or management tasks, in accordance with its own competencies.

• Lack of community involvement culture

Due to a history of relying on government, Romanians are only now learning how important it is to be involved in solving the problems of their own community. This process can be driven by local leaders who, in turn, need to be made aware of their power to solve important community problems. Community mobilization can be achieved, enhancing ownership of local initiatives, and providing an incentive to continue doing good work in the future.

III. CONCLUSIONS AND RECOMMENDATIONS

Cervical cancer is an important public health issue as it causes premature death and reductions in the quality of life. Society needs to allocate adequate resources for diagnosis and treatment. In most developed countries, both incidence of and mortality from cervical cancer have declined in the last decades, a fact largely due to the introduction of screening programs that ensure early treatment of pre-invasive lesions. Yet, in Romania, cervical cancer incidence and mortality rates have continued to increase, especially affecting younger women and leading to a significant number of potential life years lost annually. Both primary and secondary prevention must be implemented, which involves influencing behavioral risk factors as well as implementing a coordinated and comprehensive national screening program.

The benefits of Pap testing programs have been confirmed by an important decrease in cervical cancer mortality in those countries that implemented such screening programs. Screening increases the number of cases diagnosed at pre-invasive stages, thus reducing cases diagnosed at advanced, less treatable stages. A significant decrease in cervical cancer mortality can be expected 10-15 years after a high-quality screening program has been introduced.

Despite ranking first in Europe in cervical cancer rates, Romania has no coherent national cervical cancer early detection and prevention policy in place. The results of the 2004 RRHS confirmed once more the unmet need for prevention services within the Romanian population and identified the groups that are most vulnerable. These groups have difficult access to services, due either to lack of means or to distance from services. Another major problem is the lack of knowledge and awareness concerning the cervical cancer problem.

In an effort to address these issues, in 2003 the RFHI included the pilot program “Model of Intervention in Cervical Cancer Screening” within its large portfolio of activities.

The model introduced an innovative approach, focused on the population most in need, and presented some successful strategies:

- Facilitating access to early detection services by bringing the services to the population** – this was achieved through employing a well-equipped and staffed van that went mainly to isolated rural areas. The mobile unit eased access of eligible women to the program, especially of disadvantaged women facing multiple barriers including distance, transportation cost, family responsibilities, and cultural barriers. Almost three quarters of the women tested through the mobile unit were from rural areas and just 10 percent of them had been tested previously.
- Involving the family doctors** – although there is no financial incentive provided by the current legislation, the program managed to involve the GPs working in the target communities in the prevention interventions. Especially in rural areas, the family doctor is well respected and very close to the population. He/she represents the appropriate person to provide information and education to the clients. Where the specific conditions allow, the GP can also provide the Pap test, which significantly facilitates both access and compliance of the women. The program promoted the role of the family doctors and contributed to the skills building of this category of professionals, who were trained and offered the possibility to practice and be accredited for the smear taking activity.



- **Promoting and facilitating community mobilization** – local support was ensured through the setting up of initiative groups that included important members of the communities. The excellent collaboration among the members mobilized local resources and led to an increase in the impact that the information-education messages had on the target population.
- **Setting up a model of partnership** among: public institutions, having the role of scientific and methodological leadership; the civil society, carrying the responsibility of program implementation; and JSI Romania, which ensured the coordination of the program with funds from USAID.

These innovative partnerships yielded remarkable results and reached a population never exposed before to basic prevention services. An impressive number of under-privileged women benefited from free Pap testing and, maybe more important, became aware of the existence and importance of early detection and prevention of cervical cancer.

Recommendations

The program implemented under the RFHI brought innovative approaches and proved that collaboration and commitment are not only possible, but also necessary to achieve the well-being of the community. The model can be improved and extended to other regions of the country. However, in order to have national impact, a coherent, coordinated screening program must be designed and implemented. The following recommendations can be considered by decisionmakers:

- A national screening program needs political will and adequate financial allocations. Given limited resources and in order to ensure cost-effectiveness, priority should be given to high-risk groups, as determined by epidemiological analyses.
- Accountability at the level of the public health authorities should be ensured by designating program managers and designing and implementing a monitoring and evaluation strategy, including clearly defined, realistic, and easy to measure indicators.
- Screening interventions must be supported by an adequate health infrastructure, providing both testing and adequate treatment when needed. Including the program within present primary health care health services would lead to a significant reduction in cost and increased coverage, with the highest possible number of GPs participating in the program.
- There should be equal, optimal access to screening services for all socioeconomic groups through free provision of the test to all eligible women and alternative outreach services, like the mobile units, which diminish geographic and socioeconomic barriers for the underserved.
- Repeated and consistent information-education activities with the eligible female population, tailored to different cultural backgrounds, would help ensure not only primary prevention, but also an increased compliance with Pap testing.
- Personalized letters encouraging individuals to come for screening proved especially effective in mobilizing women to participate. Media campaigns also represent a good means of sharing information about the screening activities.
- Continuous training should be conducted to expand the number of medical personnel involved in screening: the GPs have to be trained to do a Pap smear; a sufficient number of pathologists, cytologists, epidemiologists, and specialists in public health must also be trained in order to carry out and evaluate a comprehensive program.
- Legislation should be revised to provide incentives for GPs that participate in the screening program and to ensure quality control of cytology laboratories, in accordance with European standards.

