# PSYCHOSOCIAL AND HEALTH SYSTEM DIMENSIONS OF CERVICAL SCREENING IN ROMANIA

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# **EXECUTIVE SUMMARY**

For the last 20 years, Romania has the highest cervical cancer mortality in Europe, with rates 6.3 times higher than the average of European Union countries. Cervical cancer is the second highest cause of cancer death in Romanian women, after breast cancer, and the first cause of death by cancer in the 25-44 age group. Besides mortality rates steadily increasing during the last two decades, cervical cancer incidence rates have also risen from 15.68 cases per 1000,000 in 1982 to 31.5 in 2000. Most cases are diagnosed in the advanced stages of the illness.

Under communist rule, Romania did not have a consistent policy for the early detection of cervical cancer. Since 1989, there have been several attempts by the Ministry of Health & Family (MHF) to develop a strategy to reduce cervical cancer mortality, but the outcomes have been unsatisfactory. The Cervical Cancer Prevention and Control Program is regulated by the Law 100/1998, and by the subprogram (2.2/2002) of the Ministry of Health & Family in accordance with European Community norms. However, due to lack of, or slow implementation at the national and local levels, chronic financial deficits, and poor management, little has been achieved. Overall, declining living standards of the population, deterioration of the medical care system, and the absence of a coherent national prevention program, contribute to the fact that cervical cancer remains a major public health problem in Romania.

#### Aims

This project was based on a fundamental assumption, that in order to produce constructive changes in cervical cancer prevention it is crucial to learn about how prevention is understood, interpreted and practiced by the people offering and receiving it. The study aimed to: (i) estimate the prevalence of cervical cancer screening among Romanian women; (ii) identify demographic and socio-economic correlates of screening behavior; (iii) assess women's knowledge, beliefs and attitudes about cervical cancer prevention; (iv) outline women's perception and experiences with health prevention and care services; (v) elicit the regulatory and financial framework, and key health care system elements within which cervical cancer screening currently functions; (vi) examine the providers' knowledge, attitudes and practices related to the current screening program; and ultimately (vii) inform policy makers and health care professionals who seek to improve the cervical screening program, and to increase women's participation in screening.

#### Methods

To reach the above mentioned goals, we used what it was called *triangulation* of perspectives and of research strategies. Both individuals' perceptions and experiences of risk, health and disease, and the professionals' perspective on these issues directed our research gaze. None of these perspectives was viewed as more legitimate than the other. We aimed to obtain broad, but also profound information on the subject, through complementing qualitative information with quantitative data obtained from a household level knowledge, attitudes and practices (KAP) survey of cervical cancer and its prevention. The study integrated two main theoretical models from health psychology and health promotion, specifically the Health Belief Model and the Theory of Planned Behaviors. We added to these psychological constructs, factors related to health care system (access, health service pathways, quality of services, information and communication systems, infrastructure and human resources, opportunity for changes, doctor-patient interaction). Our study also incorporated an interpretative and constructivism framework, which aimed to identify the lay representations of health and illness (cancer), the daily practices of preventive behavior, and the cultural constructions of women/patients' roles and responsibility in disease prevention and interaction with health professionals and healthcare system.

#### Study participants

We collected data from women, medical providers and key informants, using qualitative and quantitative methods, including in-depth interviews, semi-structured interviews, focus groups, and structured household level survey. Individual interviews with 30 *women* of different socio-economic

and educational backgrounds were conducted in order to understand how women as social actors may accept, resist or question different social practices related to health and disease. We analyzed women's perspectives and experiences on two different levels: as a general group and as unique individuals. This method also helps us to capture the dynamics between commonalities and differences among women, and to grasp the differences and similarities between health professionals and lay people. Three main sources of information were used.

A national representative sample of 1053 *women*, aged between 20-65 years, was constructed and women were interviewed face-to-face using a structured survey. The survey included questions regarding demographic characteristic, medical history, past screening behavior, knowledge, beliefs and attitudes towards cervical screening and cancer, barriers to screening, perceived susceptibility to cervical cancer, severity of cervical cancer, costs and benefits of cervical smears, intention for screening, self-perceived control and self-efficacy to ask for smear test, social support and perceived stress.

We conducted semi-structured interviews with 30 *key informants* in order to discuss the key issues of legislation and regulatory framework, funding sources, system capacity, the priority of cervical cancer screening among other health priorities, barriers and opportunities for change. Respondents included policy makers involved in developing policies on cervical cancer, leading oncologists and gynecologists, experts in public health, heads of cytology labs, the Health Insurance Fund directors, non-governmental organizations, members of the District Division of Health Care and Management of the Romanian Cancer Society and other stakeholders.

We also interviewed 50 *health care providers* and *laboratory personnel* in 9 major Romanian cities. The health care provider interviews focused on their experiences, knowledge, beliefs and attitudes towards screening programs while those with laboratory personnel focused on laboratory capacity (infrastructure and human resources), techniques and procedures, internal and external quality assurance, and needs for mass screening. The group of health care providers included family doctors (23), gynecologists (11 out of whom 6 worked for the state, and 5 for private clinics and offices), oncologists (4), family planning doctors (5), epidemiologists (1), and cytologists (6). Three *focus group* discussions were conducted with providers in Cluj, a city in western Romania. The same topic guide was used but the facilitators gave the opportunity for debate and validation of individual experiences.

# Findings

The main findings of this study are:

- A quarter of the sample (N= 1053) had not been to the doctor for a general assessment of their health status over the past 5 years, and the percentage was even higher (31.5%) in the case of gynecological exams. A higher prevalence of annual check-ups among more educated women was found.
- Our data document that Romanian women have a very low rate of participation in cervical screening programs: only 20.2% of our national representative sample reported they had ever had cervical cancer screening; 73.3% admitted that they had never received a Pap smear, and 6.5% of women did not know if they had received one or not.
- Results indicate that women over 30, with a higher educational level, married or divorced, residing in urban areas, employed, and having a good and very good financial situation and being a catholic had a higher probability of having had a Pap smear. Those with lower education and financial resources, unemployed, residing in rural areas, single and/or widowed, and Roma women, were identified as underserved groups with regards to cervical screening. It is worth noting that there was a positive relation between positive general health behaviors and history of screening: women with recent frequent use of physician services and those requesting annual general and gynecological examinations had a higher probability of also having had cervical cancer screening.

- The very low screening attendance is not so surprising as a very large number of women exhibited a lack of knowledge in this area. Approximately half of the women (46.3%) had never heard of the test before the interview. An analysis of different aspects of needed information revealed that 48.1% were not aware of the purpose of the test, nor did they know that cervical cancer is a preventable form of cancer (46.8%); about one quarter of the women who had heard about it believed the test must be repeated every 6 months and the same proportion thought that the test should be requested only when symptoms appear.
- The need for knowledge about Pap screening and cervical cancer prevention emerged as a strong theme in qualitative interviews. Most of the women did not see the Pap test as a test for health maintenance and disease prevention, but as a test for diagnosing the cause of gynecological pathology. Clearly some women did not understand the notion of asymptomatic illness.
- Women also proved to have a limited understanding of cervical cancer and misinformation about its causes. Stress, sexual misbehavior, bad diet, family history, pollution were among frequently mentioned risk factors for cervical cancer. The discourse of "dirtiness" as a risk factor also emerged from interviews. A few women did not seek a rational explanation for cervical cancer, rather they considered it to occur because of bad luck or fate.
- On investigating which barriers affected the cervical screening behavior of our respondents, the most frequently cited from a list of 15 barriers were: "My doctor never suggested it" (31.8%) and "Gynecological visits are unpleasant" (30.6%). One quarter of respondents reported that they would not go for screening for fear of a bad diagnosis, a result indicating that health education needs to inform women that cervical cancer is highly preventable if identified and treated in its early stages. Other barriers reported by women were: the high cost of service (25.5%); long lines and waiting (24.9%); smear perceived as an unnecessary test (18.2%); women's exhaustion (16%); the lack of time (15.9%); doctor's refusal to examine (15.9%); apprehension of being labeled a hypochondriac (13.4%).
- During the qualitative interviews most women reiterated the fear of being diagnosed with cancer as a barrier in preventing them to ask for a smear test. Cancer was considered to be a terminal illness and women felt that the early detection of the cancer would not be useful, as the emotional turmoil from knowing that one has a fatal disease would only add more stress to the physical disease.
- The dimensions of well-being (subjective perception of one's health, life satisfaction and feeling of control) were significantly associated with having the Pap smear test. The levels of perceived social support and perceived stress of women who had had smear test were significantly different than for those who had not. Our results reinforce the notion that the health screening behavior may be "psychosocial" in nature.
- More than two thirds of the women were dissatisfied with the experience of care they had received in a public health facility. Distress and dissatisfaction with care were shaped by factors related to the health care system but also by the health care providers' attitude. Accessibility was a frequently occurring theme. Several women described having to wait in long lines in order to get an appointment, the lack of establishing phone contact, lost results, rude and unprofessional staff, depersonalisation of care.
- A common theme in our participants' accounts was that of most clinicians failing to realize that women needed to communicate with them; physicians were criticized for not being open to answer questions, to take enough time to discuss health and treatment concerns with the patients. Women's concepts of ideal care during a visit to a doctor emphasized mutuality and interactive communication and exchange, compassion and sensitivity, but many medical consultations were perceived as being far from this ideal. Encouragement to have a Pap smear by health care professionals in the context of a relationship built upon trust and respect was described as more likely to be heeded. Training interventions for enhancing medical staff communication and counseling skills could be one of the means of addressing barriers to cervical screening.

- Women reported being largely silent in their interaction with doctors, because of feeling rushed, or perceiving doctors as distant and unapproachable. The "factory" metaphor was used by women to describe their experience of gynecological treatment in a state health care setting and the feeling of alienation as they felt that the doctor "detached" their body from their mind and soul and did not "see" them as whole people.
- Respondents also expressed discontent and anger with the "unwritten law" of informal payments that a patient should give to health providers in state health care facilities.
- Participants' accounts indicate that women seemed to theoretically value preventive care, but this attitude is not translated into practice. Most women expressed their willingness to defer medical checkups as long as they feel well. The doctor was constructed as a professional who deals only with disease and ill people, and health as feeling well and as the absence of symptoms. The gap between attitude and behavior could be the outcome of historically-framed fear and dislike of the health system, and a medical system that emphasizes the curative dimension of health care, but also the effect of the daily stress and pressure women face, and of the social construction of health as the absence of symptoms. The avoidance of preventive care could be also interpreted as a form of resistance and passive protest against a depersonalized medical system, that pays attention to the curative dimension of an ill body, but ignores the patient's needs of human caring. These results highlight the importance of educating women to have health checkups in the absence of symptoms.
- The beliefs and attitudes toward cervical cancer and smears reported by women in the survey were highly related to their intentions to conduct smears in the near future. The best predictors of intention to have a cervical smear within the next 3 months were: age, self-efficacy in relation to the behavior, attitudes toward the smear, current frequency of gynecological exams, perception of smear benefits, the psychological cost of the smear, and normative beliefs (perception of others' support of the behavior). The best predictors of screening behavior were: place of residence (urban), knowledge about cervical screening and cervical cancer, and the normative beliefs.
- Romanian health policy-makers and health care providers recognized cervical cancer incidence and mortality as a major health problem and a national cervical screening program was unanimously seen as the best way to reduce the high rates of cervical cancer mortality. However, most providers did not perceive the response of the Romanian authorities as being adequate to address the magnitude of the problem.
- Despite the existence of a legal framework for the National Program for Cancer Control, its reach is limited to a few counties. This situation was linked to insufficient funding by the Ministry of Health and to an incoherent strategy in approaching cervical cancer prevention and control.
- Most Pap smears are performed opportunistically by gynecologists, with the number of family doctors involved in this preventive strategy being very low.
- Most providers advocated the need for legislative change, in the sense that cervical screening should be financed by the National Health Insurance Fund, as part of the primary health care service.
- Many physicians were not aware of the existing regulatory framework and cervical cancer prevention implementation guidelines. This situation has led to substantial variations in practice with respect to target age groups, screening intervals, smears processing and reporting of results (the Papanicolaou nomenclature, which is now obsolete continue to be used). In addition to these problems, the Romanian screening program lacks epidemiological surveillance mechanisms that could guarantee follow-up and treatment of abnormalities detected.
- Most general practitioners do not feel they have the appropriate training to perform smear tests. At the same time they feel there are no professional and/or financial incentives for them to be involved in any aspect of cervical cancer prevention. This type of activity was perceived by physicians as being secondary to their role in curative care.

- There was a general agreement among our respondents about the lack of sufficient infrastructure to support a national cervical screening program. The number of properly trained cytologists is far from being sufficient, the profession of cyto-technician is not officially recognized and labs lack modern equipment and technology.
- There is no standardized information system for calling and re-calling women in the target age range for screening, for recording screening results, and results of diagnostic and treatment procedures. Standardized forms for collecting data within the screening programs were reportedly in use only in few counties. The importance of developing an efficient information strategy involving the accurate recording of details about screened women, monitoring and follow-up of screening results and treatment procedures was strongly emphasized by providers.
- There was no consensus among providers on whether smear tests should be obligatory or the woman's choice. Several ways to increase cervical screening attendance were proposed: from punitive measures to incentives and financial bonuses, and to empowering women to take informed decisions. However, without more effort expended on IEC activities, women will continue to be unable to do this.
- Several paradoxes emerged in the discourse of health providers. The first one was emphasizing the importance of preventive exams while stressing the priority given to the *truly sick* in their daily activities. With a few exceptions, it is clear that preventive activities consisting of check-ups are perceived by physicians as being secondary to curative ones.
- The second paradox seems to be generated by the transitional social context, in which reminiscences of the old system intermingle with "important" elements from Western societies. In other words, the paternalistic and authoritative attitude towards women (the uneducated, irresponsible individual who needs to be coerced/ sanctioned to care for his/her health) coexist with emphasizing individual responsibility and self-agency in disease prevention These mixed attitudes and messages (even if not explicit), certainly contribute to the confusion of women regarding their role in assuming the protection and promotion of their own health. Many steps still need to be taken in Romania in the direction of the patient's right to being informed, and the patient's empowerment to make informed decisions.
- The information presented in this study justifies an urgent need for interventions to reorganize cervical cancer screening in Romania through strategies for training providers, providing health care workers with incentives to undertake prevention activities, informing women about cervical cancer screening, increasing coverage, improving quality, and ensuring follow-up and treatment for clients with abnormal test results.
- This study also suggests that Romania still has a long way to go before being able to achieve screening rates comparable to those in developed countries. Such efforts should include not only influencing awareness, knowledge and perception through public education, but also reducing barriers created by the health care system, and creating a new and appropriate environment for the delivery of this important health service. Policy and political will is necessary to reach these goals.

# PART I. INTRODUCTION

# **1.1. CERVICAL CANCER IN ROMANIA**

Cervical cancer is a serious public health problem, with nearly 500,000 women developing the disease each year worldwide; it is the second most common cancer among women, after breast cancer. However, 80% of all new cervical cancer cases diagnosed annually are recorded in developing countries (WHO, 2002). It is now recognized that over 99% of cases in all countries are related to certain types of the human papilloma virus (HPV). The virus is acquired mainly through sexual activity (Bosch & Munoz, 2000). Among all malignant diseases, cervical cancer is the one for which prevention efforts have been the most successful in the Western world. The incidence and mortality rates due to cervical cancer have been declining significantly in most developed countries since at least the 1960s. During the past 50 years, Pap cytological screening has reduced about three quarters of this disease burden in developed countries (Waggoner, 2003).

The transition from communism to market economy and democracy seems to be paralleled by a dramatic deterioration of public health, indicated by a falling life expectancy and rising mortality. Romania, as other Eastern European countries, has faced major changes in the patterns of mortality and morbidity. The incidence of malignant tumors has rapidly increased, these representing the second cause of death, after cardiovascular diseases. With a standardized mortality rate of 11.02 per 100,000 in the year 2000, cervical cancer is the second highest cause of cancer death in Romanian women, after breast cancer, and the first cause of death by cancer in the 25-44 age group (Nicula, 2002). For the last 20 years, Romania has the highest cervical cancer mortality in Europe, with rates 6.3 times higher than the average of European Union countries (Dobrossy, 2002; WHO, 2004) [Figure 1]. Furthermore, rates have been increasing, with death rates 15% higher in 2000 than in 1990.



**Figure 1.** Standardized mortality rates for cervical cancer (0-64 age), per 100,000 Source: Health for All Data base (WHO, 2004)

At the global level, Romania has the fourth highest mortality rate due to cervical cancer among 45 countries that report cancer statistics to the WHO, surpassed only by mortality rates reported by Mexico, Venezuela, and Chile (WHO, 1999). According to the WHO database (2001), cervical cancer mortality rates in Romania are approximately 2-2,7 times higher than in most Eastern and Central European countries (Table 1). Since 1997, over 1,700 cervical cancer-related deaths have been recorded annually in Romania (Nicula, 2002).

Table 1. Standardized	mortality rates f	or cervical	cancer in	Central a	and East	Europe in	2002
(Source: GLOBOCAN,	2002, IARC)						

Country	Mortality rates (per 100,000)
Romania	13.0
Poland	7.8
Hungary	6.7
Bulgaria	8.0
Moldavia	7.8
Serbia & Montenegro	10.1
Czech Republic	6.2
Albania	9.8
Ukraine	6.1
Slovenia	4.7
Slovakia	6.1
Russian Federation	6.5

Besides mortality rates steadily increasing during the last two decades, cervical cancer incidence rates (standardized) have also risen (from 15.68 cases per 100,000 in 1982 to 31.5 in 2000). Romania again holds first place in Europe, with the highest cervical cancer incidence (Table 2). Age-specific incidence increases between 20 and 49 years of age, reaching its peak in the 45-49 age group, with an incidence of 9.58 per 100,000 (Suteu, 2001). The rising trend in cervical cancer mortality does not only reflect its increasing incidence, but also the advanced stage of the disease at the time of diagnosis. Most cases (over 50%) are diagnosed in the advanced stages of the illness (II to IV) (Socolov, Anton, Azoicai et al, 2000).

**Table 2.** The standardized incidence and mortality rates (100,000) for cervical cancer in Romania (Ministry of Health, 2002a).

Year	Incidence rates	Mortality rates
1982	15.68	9.6
1985	17.50	10.4
1990	12.59	10.1
1995	17.09	10.1
2000	31.5	11.2

Cervical cancer is the first type of cancer for which systematic screening programs have been developed using the Papanicolaou smear. The goal of screening is the early detection and treatment of asymptomatic pre-cancerous lesions, preventing progression to cancer. Morbidity and mortality rates are thus reduced, compared to detecting the illness in clinically active stages. In countries where screening programs has been available since as early as 1950-1960 (such as Canada, the USA, the United Kingdom, and Northern European countries), cervical cancer rates have fallen to low levels (by up to 60% in those countries where screening is well organized and coverage rates are high). Cervical cancer mortality rates in 2000 were: 2.8/100,000 in Canada; 3.3 in the USA; 1.3 in Finland; 2.9 in Sweden; and 3.9/100,000 in the United Kingdom (Levi, Lucchini, Negri et al, 2000). Mortality rates in Romania (11.2/100,000) are 8 times higher than in Finland, the country with the lowest cervical cancer death rate.

Despite the fact that the early detection of cervical cancer is possible, a systematic national screening program has never been implemented in Romania, neither before nor after the political changes in 1989. In this context, the cumulated risk of a Romanian woman developing cervical cancer

during her lifetime is 2.23% compared to the USA, where the risk is estimated at 0.8%. In other words, in Romania 1 in 44 women will develop cervical cancer during their lifetime, compared to 1 in 125 in the USA (Suteu et al., 2002a).

There have been several attempts by the Ministry of Health & Family (MHF) to develop a coherent strategy to reduce mortality through cancer, but the outcomes have been unsatisfactory due to lack of implementation at the national and local levels, chronic financial deficits, and poor management. Information on screening coverage rates after 1990 is scarce and contradictory. The Reproductive Health Survey conducted in 1993 by CDC-USA in collaboration with the Romanian Institute for Maternal and Child Protection indicates a 15-25% coverage of reproductive age females, (Serbanescu & Morris, 1993) although some specialists consider these figures higher than real rates. Another national study, conducted in 1997 indicates national screening coverage rates of 7.4% (with rates varying from 0.5-17% from one area to another) (Romania/National Statistic Institute, 1997). The Reproductive Health Survey, repeated in 1999, indicates a 17% coverage rate (Serbanescu, Morris & Marin, 2001).

Because of the declining living standards of the population, the deterioration of the medical care system, and the absence of a coherent national prevention program, cervical cancer remains a major public health problem in Romania. The next section describes the organization and function of the Romanian health care system during the communist regime and after the political changes in the late 1980s.

# **1.2. ROMANIAN'S HEALTH SYSTEM**

The health care system in pre-1989 Romania was typical of Central and Eastern European countries. The main features of the health care system during the four decades of communism were: government under-financing, ineffective intersectoral coordination, central planning, rigid management and a state monopoly over health services. The state provided low quality health services to all members of the society, seeking to achieve a universal coverage of health care but leaving little or no choice to the use. This induced a low individual responsibility, as Romanians were used to the fact that state institutions took care of their health.

The medical system was heavily-medicalized, with an accent on the medical specialist and clinical treatment. Patients had direct access to specialists in the ambulatory system (policlinics). The field of family medicine was practically non-existent before 1990, with the role of GPs in factories and urban dispensaries often limited to guiding patients to specialists, or to writing documentation for medical leaves. GPs in more isolated rural dispensaries had a much broader area of responsibility: from assisting births in the case of women who did not make it to maternity hospitals to treating patients who could not be transported elsewhere, as well as assisting acute conditions in both children and adults. Preventive activities conducted by the institution called "Sanepid" concerned mainly infectious disease control. Preventive medicine oriented towards the individual was practically non-existent, as medical examinations of healthy persons were discouraged in medical guidelines. Medicine was focused on disease diagnostics and treatment.

During the last 23 years of the former regime, reproductive health promotion was focused mainly on one goal, namely ensuring a high birthrate and fertility rate, regardless of the individual and social costs (David, 1999). This state policy was imposed through drastic coercive and punitive measures: forbidding the production and import of contraceptive methods, forbidding abortions for women under the age of 45, compulsory gynecological exams every three months, taxes for childless individuals and couples, imprisonment of providers and of women discovered to have had an abortion (Kligman, 1998). Over 10.000 women died following medical complication of illegal abortions, resulting in maternal death rates almost 10 times higher than the European average in 1989. During 1966-1989, as part of the draconian pronatalist policy of the regime, cervical cancer screening was sometimes used as a pretext for compulsory gynecological exams at the workplace, with the purpose of identifying pregnant women. In this context, most gynecologists were perceived by many women as collaborators of the repressive state structures, doctors only turned to as a last resort or when wanting

a pregnancy. The traumatic experience of many women who were discovered having an unwanted pregnancy and being officially recorded, or of those who were forced to turn to gynecologists in emergency situations following self-induced abortions, still lingers on in the minds of many women (Baban, 1994, 2000).

The collapse of the former political and socio-economic system has had a strong impact on the publicly funded health sector. The current performance of the health sector reflects the legacy of a system that emphasized a medical rather than a public health model, focusing on treatment rather than prevention, and on institutions rather than on people they serve. Among other legacies, which undermine the current health system are: the relatively small proportion of the GDP dedicated to health care; the inequitable allocation of resources; the lack of response to local needs; the poor quality of first level services; inadequate investment in equipment and facilities; growing inequity in health care provision among regions and different social groups; and a poor managerial capacity within the health care system (Vladescu, Radulescu, Olsavsky, 2000).

#### 1.2.1. Organizational Structure of the Health Care System

The Romanian health care system is in a process of rapid transformation. Starting in 1997, important laws concerning the structure and organization of the health care system have been passed. The new regulations have practically changed the entire structure of the health sector and established the legal framework for the shift from an integrated, centralized, state owned and controlled tax-based system to a more decentralized and pluralistic, social health insurance system, with contractual relationships between health insurance funds, as purchasers, and health care providers. The aim of the reform was first to improve primary health care and then to privatize the health services sector. However, there were important delays in the implementation of the new health insurance scheme and in decentralizing the health care system.

Since 1999, the main actors involved in the health care system have been: the Ministry of Health & Family and the District Public Health Directorates; the National and the District Health Insurance Funds; the Romanian and the District Colleges of Physicians; and the health care providers. The creation of the health insurance fund and the introduction of a new method for purchasing health care services has had a substantial impact on the role of the Ministry of Health & Family (MHF). Since 1998 - the transitional year - the MHF has been responsible for health policy making, setting organizational and functional standards, and developing national public health programs. At local level the MHF acts through 42 district public health directorates. A new role of the MHF is that of a regulator of Romania's emerging private health sector. However, legal changes of roles and responsibilities of the MHF have not been yet associated with significant changes in skills, competencies and attitudes of policymakers (Vladescu, et al., 2000).

The National Health Insurance Fund (NHIF) is a specialized public institution that sets the rules for the functioning of the social health insurance system. The NHIF negotiates the framework-contract with the Romanian College of Physicians, which sets up the benefit package to which insurees are entitled and the resources allotted between types of care. District health insurance funds are in charge of raising social health insurance contributions from employers and employees working in the respective districts. They are also responsible for reimbursement of local providers, both individual providers, (i.e. physicians), and institutional providers, (i.e. medical facilities such as hospitals and outpatient centers). They finance mainly curative services on a contractual basis. The main role of the National College of Physicians is to set medical professional standards and to offer professional support to physicians.

#### 1.2.2. Health Service Financing

Prior to 1998, Romania's health care system was financed mainly by government revenues received from direct and indirect taxes, but also from local government budgets, from the Special Health Fund and from some external sources. Since 1998, the main source of financing of the health system has been health insurance (77% in 2000); tax is another source of public health finance (15.1% in 2000). The Health Insurance Fund mainly consists of contributions paid equally by

employees (7% of the total income) and employers (7%), and contributions paid by the state for the unemployed, pensioners, and other deprived population groups (Vladescu et al., 2000).

Health expenditure from public sources varies between 2.6% and 3.8% of the GDP, or US \$30–60 per capita, compared with the EU average of 8.5% and the East-Central European average of 5.5% (WHO, 2002). The National Health Insurance Fund allocates budget to the District Health Insurance Funds in accordance with a formula based on the number of insured persons and the mix of population risks for ambulatory, inpatient and dental care. Family doctors are paid via a mix of weighted capitation (70%) and 'fees for services' for preventive and health promotion services. The payment of specialists in ambulatory services is done by a 'fee for service' schedule, based on a points system. Hospitals are paid by global budgets set on a historical basis (70%) and on performance criteria (30%).

Free health care services are guaranteed to all employees and their families, pensioners, selfemployed and unemployed people, children up to the age of 14 and pregnant women. Co-payments are required for drugs. Officially, no payment is required at the point of delivery for most services, but "under-the-table" payments to health care providers are still common in Romania. There are data suggesting that out-of-pocket payments for health services is around 50% of the real cost (Vladescu et al., 2000).

Owing to the division of health services into private and public, many people get much worse health services than before because they cannot afford to pay for private health services, while public health services have deteriorated. Reduced access to health care has been especially high in rural areas, where the migration of health professionals to cities, coupled with inadequate investment in equipment and facilities has led to the deterioration of services. Romania has a four years difference in life expectancy between different regions (poor and better off) of the country (National Statistical Institute, 2000).

#### 1.2.3. Health Service Structure and Provision

The health care delivery system has also changed during the same period. Primary care has been "the neglected service" for a long time, and has required continued reform attention. Until 1998, *primary health care* was mainly performed through a countrywide network of about 6000 dispensaries. There were also factory-based dispensaries for employees, and school dispensaries providing medical care for anyone in full-time education. Patients were not allowed to choose their dispensary, but were assigned one according to their place of employment or residence. The family doctor is now an independent professional paid by the National Health Insurance Fund on a contractual basis. Starting with 1998, patients have been allowed to choose their family doctor, who may be changed after a minimum of three months after initial registration with that doctor. At the end of 2000, 83% of the population had registered with a family doctor. The family doctor now has the role of "gate keeper"; patients cannot access a specialist unless they have a referral from their family doctor, but this referral system has been continually bypassed. On average in 1998, patients consulted the primary health care doctors 2.3 times a year, accounting for only a third of all ambulatory care contacts (Vladescu, 1999).

In 2000, secondary care services were provided by 442 hospitals, of which 3 were private hospitals. Ambulatory secondary health care is delivered by the network of centers for diagnosis and treatment and office-based specialists. Previously, the "typical" secondary care providers were polyclinics, which were located in urban areas only (while the dispensaries were in both rural and urban areas). Individual medical offices of specialists are starting to be set up in rural areas as well, but generally they are based in towns. Romanian hospitals are divided into four categories: 1) rural hospitals providing internal medicine and pediatric services (maximum 120 beds); 2) town hospitals (250 beds) and municipal hospitals (450 beds) with departments of internal medicine, surgery, obstetrics & gynecology, and pediatrics, 3) district hospitals (450 to 1000 beds) with additional departments of orthopedics, intensive care, ophthalmology and oto-rhino-laryngology and 4) specialized units for tertiary care (such as teaching hospital institutes, and institutes for maternal and child care, the oncology institutes, the neuro-surgery hospitals). The number of hospital beds per 1,000 inhabitants has decreased from 8.9 in 1990 to 7.4 in 2000. This level is still above the EU

average of 6.9 beds per 1,000 inhabitants, but the Ministry of Health and Family is continuing the process of reducing bed numbers. The high hospitals admission rates would support the hypothesis that patients are admitted directly into hospital without proper care in outpatient clinics. The average length-of-stay, excluding chronic care hospitals, is at about 9.5 days (similar to the CEE average, but still above most western European countries) (Vladescu et al., 2000). Many hospitals have poor conditions and inappropriately maintained buildings. The vast majority of both hospital and polyclinic medical equipment (X-ray facilities, laboratory facilities) can be judged obsolete.

## 1.2.4. The Health Promotion and Education

Until 1990, health education was referred to as "sanitary education", and focused on hygiene aspects of health. Since then great emphasis has been put on changing "sanitary education" into a network for health promotion and education. In 1992, the National Center for Health Promotion and Education for Health was set up, as a department of the Institute for Health Services Management. However, only about 1% of the total project, consisting of US\$150 million received from the World Bank for the health system reform, was allocated to public health and health promotion. Due to the weak government support and the lack of a clear framework for health promotion, the originally envisaged establishment of a health promotion fund from the World Bank, was cancelled (World Bank, 1999).

## 1.2.5. Human Resources and Training

The most recent Ministry of Health & Family data (1998) indicate that Romania has one practicing physician for every 580 people, or 17.7 per 10.000 people, (i.e. over 41.000 doctors). The average number of physicians per bed (excluding chronic care hospitals) shows one physician per ten beds. Unlike in most other countries, this number has not changed during the 1990s. This average number, however, hides the geographic and medical specialty mal-distributions and the quality dimension, which are both important issues. The number of nurses (40.8 per 100.000 population) and of midwives (39.5 per 100.000) is much lower than the rates of the other Central and East European countries. The social status of doctors and other personnel from the health care sector is low, relating directly to their wages. The average wage in the health care sector is below the national average wage as calculated by the National Commission for Statistics.

One of the great changes brought about by the health care reform has been the development of family medicine as a new area of specialization in medicine, following a 4 year postgraduate training program, as in the case of other medical specializations. The goal of the Ministry of Health & Family through this new regulation was not only to further develop knowledge and skills, but also to change the status of the family doctor/GP. Up to not very long ago, the GP used to be perceived, both by colleagues and the general population, as a physician with insufficient professional training or lacking professional interest to practice "real medicine" (Bara, van den Heuvel & Maarse, 2003).

Physician medical training, regardless of specialization, continues to be quite bio-medically oriented. It lacks significant aspects such as concepts of public health, the psychosocial dimension of illness and doctor-patient communication. There is little emphasis on health promotion and maintenance within the community; the focus is mainly on treatment in the clinical setting. The recent strategic, epidemiological and burden of disease changes in the country require new training modalities, as well as massive retraining of all service providers at all levels.

# 1.2.6. Health Policies

Romania has not yet produced a fully articulated, written health policy, although the Governance Program for 2000-2004 included health amongst its priorities. The main health related objective was "a healthier Romania with a lower morbidity and fewer premature deaths". The Romanian health care reforms are intended to follow some principles such as accessibility, universality, solidarity in funding health services, incentives for effectiveness and efficiency as well as providing service delivery linked to health care needs. These principles are officially based on legislation and policy measures. But legislation does not always mean that the policy measures are implemented in practice and a discrepancy exists between policy and practice. Moreover, health

legislation is very complex and changes almost monthly. This can be illustrated by the Health Insurance Law, which was adopted in August 1997 and has been amended several times since. Constant change complicates a coherent decision-making process and a sound management of the system, both at macro level and at the micro level (Vladescu et al., 2000).

# **1.3. THE INSTITUTIONAL FRAMEWORK OF CERVICAL CANCER PREVENTION**

As shown in section 1.1, cervical cancer is a major public health issue in Romania, with the highest incidence and mortality rates in Europe, and rates that continue to rise. Cervical cancer mortality rates in the year 2000 were 15% higher than in 1990.

Romania has not had a consistent policy for the early detection of cervical cancer, neither before 1989, nor after 1989, when the scarce financial resources were directed towards curative medicine, rather than disease prevention. During 1991-1995 and 1996-2002 several initiatives were taken by the Ministry of Health & Family to develop a national strategy for reducing cancer mortality (in general). None of these initiatives has been finalized through the implementation of coherent programs. Among the causes of failure discussed here are: inadequate budgets, inadequate management, frequent changes within the Ministry of Health and the National Health Insurance Fund, and an inadequate legislative framework.

The Romanian Cervical Cancer Prevention and Control Program is regulated by the Law 100/1998 of the Ministry of Health & Family in accordance with European Community norms. However, implementation of this program has been very slow. A 2000 USAID report assessing the capacity of the Romanian medical system to adequately address the increased rates of cervical cancer mortality, concludes: there is insufficient infrastructure to support cytological laboratories; there is an insufficient number of qualified cytologists; there are no cyto-technicians; the Giemsa staining method is used instead of the Papanicolaou staining method, and the old Papanicolaou classification system is used instead of the Bethesda system; there is no accreditation of cytological labs; there are no methodological guidelines for the internal and external quality control of cytological activities; smears taken by physicians are often inadequate; the number of false positive and false negative results is very high; patient records are not standardized; there is no system for monitoring women with pathological test results. All these negative aspects significantly impact on any attempts to promote cervical cancer screening among Romanian women (Vladescu, 2004).

Pilot programs with foreign funding have been implemented in some counties. The first pilot programs are that financed by the Open Society Foundation Romania, during 1999-2000, in the county of Cluj (Suteu, 2002a, 2003), and that implemented in Bucharest and surrounding rural areas in 2001, with the financial support of the Open Society Institute, New York. During 2002 and 2003, the Ministry of Health financed two more pilot programs in Bucharest and lasi.

In 2002, the Ministry of Health established the Oncological Pathology Prevention and Control Subprogram (number 2.2) as part of the National Health Program. Regarding the prevention of cervical cancer, the subprogram includes the following three dimensions: (1) reorganizing regional and national cancer records; (2) cervical cancer prevention through raising awareness, education and screening; (3) specific treatment provision through early diagnosis methods including: repeat cytology and colposcopy and appropriate treatment based on patients' medical assessment. Initially, this program was implemented in 3 of the 42 counties in Romania; it was extended to 9 other counties in 2003, and has continued in these 12 counties during 2004. The prevention dimension of the program has the following short-term objectives: an approximately 80% participation rate in the screening program of women 25-65 years of age; a below 5% rate of uncertain test results; and monitoring women of with abnormal test results over a period of three months. Medium term objectives include a 30% decrease in advanced stage cancer diagnoses. The long-term goals are a 60% decrease in cervical cancer incidence over a period of 10 years, and a 60% decrease in mortality over a period of 20 years. This program is being subsidized by state and nongovernmental funds, therefore Pap smears are charge-free for women who are registered residents of counties included in the program (Suteu, 2002b).

According to an assessment conducted by the Center for Health Policies and Services in 2003, (Vladescu, 2004) Romania does not have a functioning national screening strategy for cervical cancer, but only a few pilot projects in some of the counties. Referrals for screening are not being given routinely at primary care sites; the number of GPs that are part of this process is very low; Pap smears are usually taken on an opportunistic basis by gynecologists; women usually have to specifically request them and/or pay for them; there is a great confusion regarding staining and classification methods that should be used to get results; there are no quality control standards for cytological activities; cervical cancer screening is not part of the national insurance health plan, therefore women have to pay for a smear test (unless required for symptomatic diagnostic reasons, when covered by the national insurance health plan). The goal of the assessment was then to create a framework for the development of a National Public Health Strategy for cervical cancer prevention, and to elaborate a model for coordinating and managing screening programs at regional/local levels. To reach these goals, the Center for Health Policies and Services, in cooperation with the Ministry of Health, and the JSI Research and Training Institute, has developed:

- o Guidelines, norms and methodology for cervical cancer control;
- Smear examination protocols;
- Reference centers for cervical cancer control;
- Internal and external quality control criteria;
- o Information system for setting up appropriate patient records and follow-up;
- Training for family doctors;
- Training materials for physicians.

#### 1.3.1. Norms for Prevention and Treatment of Cervical Cancer

The Guidelines and methodology for cervical cancer prevention and control in Romania include the following norms:

- All sexually active women should be encouraged to have cervical cancer screening, except for: women who have had a complete hysterectomy for a benign condition, women over 69 years of age who have had two consecutive Pap smears at recommended intervals, and whose results are within the normal range.
- However, considering the human and financial resources of Romania at present, the target group that testing should be focused on at the initiation of the National Screening Program is women between 35-69 years of age. The interval between consecutive tests should be 3 years at the most, although ideally annual screening of the target population is recommended. When greater human and financial resources for the National Screening Program become available, the age range of the target population will be expanded to women between 25-69 years of age. Women over 69 who have *never* taken the test should have two consecutive screenings, at a 6 months interval; if results are normal, testing can be discontinued.
- Women at high risk of disease progression (those with abnormal results at a recent Pap smear), will be carefully monitored, first by repeating the test after a three month period.
- Smear staining will no longer be done using the Giemsa staining method, but the Papanicolaou staining method.
- For reporting results, the Bethesda 2001 classification system will be used instead of the CIN system.
- The interval between the smear and the communication of the result to the physician taking care of the patient should be between 3-7 days.
- Standardized forms for requesting the test and reporting results will be used.
- > Pap smears will only be taken by trained personnel, particularly by GPs.
- > Internal and external quality control criteria for monitoring lab activities will be established.
- A National Cancer Registry will be set up for monitoring the number and identity of screened women, cytological results, and follow-up methods of problematic and clinical cases.
- It is recommended that the payment of medical doctors taking Pap smears be done by the National Insurance Fund, as a payment for prevention services.

In the findings sections of this report, we highlight *whether, how and when* these norms are implemented in the *real life conditions*, from both perspectives, of beneficiaries and providers.

# Part II: METHODOLOGY

# 2.1. PROJECT AIMS

This project is based on a fundamental assumption, that in order to produce constructive changes in cervical cancer prevention it is crucial to learn about how prevention is understood, interpreted and practiced by the people offering and receiving it. The ways of making sense of health, risk, disease and prevention may differ radically between layperson perspectives and biomedical explanations. Cervical screening can be considered a sensitive situation involving both the risk of a potentially life-threatening illness, and a medical examination that interferes with emotions and beliefs about body, sexuality, privacy and womanhood. Disparities between the perception of screening programs by beneficiaries and those providing them can lead to poor or minimal effects on screening behavior. Improving cervical screening behavior among women requires that health policy makers, health care providers and women themselves share a common perspective about prevention practices.

While we currently have information on cervical cancer incidence and mortality in Romania, little is known about the factors influencing preventive screening behaviors. To date no studies have been conducted in Romania to determine the systemic and individual factors that might act as barriers to positive screening behavior. To address this gap we initiated a project to identify the interconnectedness between screening behavior, the health care system, and women's demographic, socioeconomic and psychosocial characteristics. More specifically, the purposes of this project were:

- > To estimate the prevalence of cervical cancer screening among Romanian women.
- > To identify demographic and socio-economic correlates of screening behavior.
- > To assess women's knowledge, beliefs and attitudes about cervical cancer prevention.
- > To outline women's perception and experiences with health prevention and care services.
- > To elicit the regulatory and financial framework, and key health care system elements within which cervical cancer screening currently functions.
- To examine the providers' knowledge, attitudes and practices related to the current screening program.
- > To inform policy makers and health care professionals who seek to improve the cervical screening program, and to increase women's participation in screening.

# **2.2. THEORETICAL FRAMEWORK**

To reach the above mentions goals, we used what Denzin (2000) called *triangulation* of perspectives and of research strategies. Both individual's experiences of lived risk, health and disease, and the professionals' perspective on these issues directed our research gaze. None of these perspectives was viewed as more legitimate than the other; our aim was to give voice to stakeholders of different perspectives.

The project also aimed to obtain broad, but also profound information on the subject, through complementing quantitative data with qualitative information obtained from a household level knowledge, attitudes and practices (KAP) survey on cervical cancer. Although KAP studies can provide important descriptive information, they are by their nature limited by unexplained confounding variables, which cloud our understanding of women's conceptualizations of their health prevention experiences. Understanding of health and illness behavior is incomplete unless an attempt is made to capture the subjective reality of the individual's perspective. This is best accomplished thorough the use of in-depth interview, which is a useful tool for gaining access to the manner in which social actors involved (or not involved) in preventive behavior describe, interpret and explain the world they experience. The attempt of this project to combine and integrate different types of data and perspectives was made with the ultimate goal of achieving, through the negotiation of different viewpoints, a comprehensive understanding of circumstances and ways that might lead to the improvement of the cervical screening programs in Romania.

To study women's perceptions, beliefs, attitudes and practices relevant to cervical screening we developed a comprehensive theoretical model, which is depicted in Figure 2. The model integrates constructs from two main theoretical models in health psychology, specifically the Health Belief Model (HBM) (Rosenstock, 1990) and the Theory of Planned Behaviors (TPB) (Ajzen, 1991), which are widely use to investigate screening behavior. We added to these psychological constructs, factors related to health care system (e.g.: access, pathways, doctor-patient interaction). Based in social cognitive psychology, the Health Belief Model and the Theory of Planned Behavior provide frameworks to change behavior by addressing the individual's beliefs, subjective norms, and perceptions of control and risk. The underlying assumption of these models is that inducing individual behavior change requires more than the provision of knowledge alone. The Health Belief Model synthesizes the effects of expectations and threats in order to motivate behavior change. Both expectations and threats depend on a specific set of knowledge, as well as a specific set of interpretations of danger and risk. When individuals fail to perceive appropriate levels of severity and susceptibility, it becomes the public health educator's responsibility to elucidate this risk. While the Health Belief Model explores the motivators for action, the Theory of Planned Behavior, synthesizes Beliefs, Social Norms and Perceived Control to acquire behavior change. We chose these conceptual frameworks because they assume that factors affecting health behaviors might be culturally influenced (e.g. beliefs, norms) but because they also allow us to predict the determinants of screening intention and behavior across communities.

To understand how the health system works for implementing a cervical cancer screening program we collected data on regulatory and financing mechanisms, functions and links, infrastructure and human resources, access and quality of services, information and communication systems, and opportunity for changes, based on the model depicted in Figure 3. Health care providers play an important role in cervical cancer prevention by providing information and services. Actions taken by them are likely to be shaped not only by professional regulations, but also by their beliefs, perceptions and attitudes towards cancer prevention and women's role in prevention. Such perceptions and beliefs are relevant to the potential impact that health care providers can have in changing preventive practices among Romanian women.



Figure 2. Psychosocial Model





# 2.3. METHODS

## 2.3.1. Semi-structured Interviews with Women

The importance of exploring lay constructions of health, disease prevention and biomedical procedures, such as cervical screening, personal experiences of care service access and availability, as well as patient-doctor encounter, led us to conduct individual interviews with women. All the interviews were guided by a themes list. Interview guides included the following topics: women's experiences with their healthcare providers; understandings and explanations of cervical cancer risk; perception of their own risk for cervical cancer and of the utility of Pap smears in preventing it; feelings about gynecological exams; beliefs about responsibility towards maintaining health. To gain a better understanding of women's perceived needs for prevention and care services, we asked them to describe ideal ways of informing women of cervical cancer screening and of access to Pap smears and screening results. Questions designed to elicit concrete answers were combined with open-ended questions so that respondents could describe their experience in their own words. There was no specific sequence of questions, and interviewers were trained to follow and respect the participants' sequencing, while making sure that most themes of the interview guide were ultimately covered.

#### 2.3.2. Structured Interviews with Women

A structured questionnaire was developed, informed by the above-described psychosocial model. Besides the variables of the HBM and TPB models, we included other psychosocial variables for addressing Pap testing barriers and facilitators, such as: social support, health locus of control, perceived stress and life satisfaction. The survey was also constructed to be culturally sensitive to the needs of Romanian women and the current context of health care, using the information gained from the qualitative interviews. The structured questionnaire contained the following sections:

- Demographic characteristics of participants (age, education, profession, employment status, marital status, ethnicity, religion, place of residence, income).
- Medical history: last medical check-up, frequency of medical visits in the last 12 months, frequency of gynecological exams, self-perceived health.
- Past screening behaviors: experience with cervical smears, when, how often, and who took their smears.

- Knowledge about cervical cancer and cervical cancer screening methods (measured by 5 items); we also asked about sources of information about smears.
- Pathways within the medical system: questions were asked about who suggested screening (client or provider), referral history, payment for services, history of ever being refused a smear, and experience with receiving results, and repeating smears.
- Perceived barriers to cervical screening: fifteen items describing affordability, availability of information, access to clinics, and attitudes of medical providers assessed the extent to which certain problems are important for women when seeking care.
- Cognitive constructs: the constructs from the Health Belief Model assessed beliefs about screening through a 21 items, including perceived susceptibility to cervical cancer, severity of cervical cancer, costs of cervical smears and benefits of smears. The constructs from the Theory of Planned Behavior included attitudes toward screening, perceived behavioral control, self-efficacy in relation to screening, and descriptive and injunctive subjective norms. Attitudes were assessed through a semantic differential containing 5 items, while the other constructs (self-efficacy and perceived behavioral control) were assessed by one item each.
- > Intention to undergo cervical screening in the following three months (one item).
- Psychosocial constructs: life satisfaction (1 item), perceived stress (6 items) social support (5 items) and health locus of control: internal, powerful others and chance health locus of control (6 items for each subscale). To measure the extent of the belief that health is determined by one's behavior, we used the short version of the Multidimensional Health Locus of Control (M-HLC) model, developed by Wallston & Wallston (1978). The internal HLC assesses the extent to which individuals believe they are responsible for their health, the extent to which they believe they can avoid behavior that increases the risk for disease; the chance HLC subscale focuses on a person's views regarding his or her health and sickness as a function of external forces, such as luck, fate or accident; the "powerful others" HLC subscale assesses the extent to which individuals believe that powerful others, particularly physicians and nurses are responsible for their health and illness.

#### 2.3.3. Semi-structured Interviews with Health Care System Professionals

Interviews were conducted with health professionals (key policy and planning informants and health providers) to determine their perspectives on the current organization and financing of the cervical cancer screening services, the advantages and disadvantages of the system; linkages and responsibility for screening, and suggestions for change. The extended guide of interview included the following topics:

- Prevalence of disease: knowledge of the rates of cervical cancer incidence and mortality in Romania and how they compare to other countries and to previous periods.
- Prioritization of cervical cancer and screening: knowledge of, and opinions on how prevention and management of cervical cancer compares with other health priorities of the country.
- Policy and regulatory framework: knowledge of existing national strategies, Ministry of Health policies and guidelines for cervical cancer screening and use of screening protocols.
- Programs and institutional arrangements: knowledge of institutions monitoring cervical cancer prevention and providers' relationships with these institutions.
- Funding: information on what components of cervical cancer prevention and management are funded in Romania, the legal basis for these payments, and payment sources.
- Infrastructure and capacity: information about who is taking Pap smears, who is trained to take them, what is the number of smears being taken, what equipment is being used and available, what is the role of the cytology laboratories.
- Professional roles: information on providers involved in early detection and on the role of the general practitioners, gynecologists, and cytologists.
- > Access: how women get screened and if necessary, treated.
- Practical procedures: information on whether screening is part of routine care and how providers decide who should be offered smear tests. Details of what technology is used, and of how positive results are dealt with.

- Communication: details of how patients are informed about screening and whose responsibility it is to inform them.
- Information: details of how client screening and treatment information is stored and aggregated, both locally and nationally.
- Overall assessment: information on the professionals' overall evaluation of the existing cervical cancer prevention system and on suggested reforms.

# 2.4. STUDY PARTICIPANTS, DATA COLLECTION AND ANALYSIS PROCEDURES

#### 2.4.1. Semi-structured Interviews with Women: Sample and Data Collection Methods

Interviews were conducted with 30 women. Purposive sampling was employed on the basis of: socio-economic and educational backgrounds, and past screening history. Half of the interviewed women had previously had a Pap smear, while the other half had not. Four pilot interviews were conducted using a preliminary guide. The guide was then finalized into a form that was used for the rest of the interviews. Informed consent was obtained verbally. Tact and non-judgmental attitude were the keys to encouraging women to speak about sensitive issues. Interviews lasted from 40 to 80 minutes, averaging 60 minutes. All the interviews were tape-recorded with each informant's consent. The interviews were conducted over a period of six months (May-October 2004) by four researchers. All interviewers were women and psychologists.

The interviews were tape recorded and transcribed verbatim. Several strategies were used to analyze the data. The analysis was guided primarily by a version of what Smith (1999) has termed *interpretative phenomenological analysis* and by the procedures of grounded theory (Charmaz, 1999). A computer software package (Atlas.ti, 1997) was used to manage, code and explore the data. The analysis of the interviews followed the technique of thematic decomposition. The term "theme" is used here to refer to the researcher's identification of coherent patterns in the participants' accounts (Baban, 2002). The identified themes were also used to develop the structured questionnaires for the representative sample of women. Our assumption was that women are actors who may accept, resist or question different social practices related to health and disease, depending on circumstances and contexts. We analyzed women's perspectives and experiences on two different levels: as a general group, through the identification of commonalities and differences; and as unique individuals. The quotes from participants illustrate their perceptions, beliefs and attitudes.

Because the qualitative analysis is based on small numbers, research findings are not presented numerically. Instead, terms such as most or many (more than half), several, and a few (usually two to five women) are used to provide an indication of the frequency of a particular interpretation or theme. Qualitative information obtained from individual interviews conducted with women was compared with quantitative data. This method helps us to capture the dynamics between commonalities and differences among women, and helps us to grasp the differences and similarities between professionals and laypeople.

#### 2.4.2. Structured Interviews with Women: Sample and Data Collection Methods

The database for the design of a representative random sample of Romania's 20-65 year old women was the 2000 Census (National Institute of Statistics, 2000). A multi-stage cluster sample was used, where in the first stage, the preliminary stratification of the sample database was based on the cross tabulation of geographical areas and settlement size. The number of people to be questioned was calculated for each strata by using the weight of strata in the population, which ensures the representativity of all regions of the country. From each strata was selected randomly households. All women aged 20-65 in the households were included in the study. The response rate was 90.4%, and in the case of refusal to participate in the study, the next household was selected. A nationally representative sample was built this way, comprising 1053 women, aged 20 – 65. Demographic characteristics of the final sample are presented in part III of the report.

Data were collected by thirty-five interviewers with prior experience in conducting surveys, between June and August 2004. In order to reach women in the sample, as many as 3 visits were

planned for each household during the day, evening and weekends. The survey, which took 40-50 minutes to complete, was conducted in privacy at the respondent's home after the aim and procedure was explained to every participant and she consented to participate. Interviewers used a standard verbal script to inform potential participants in the study on research aims and their rights. Participants provided verbal consent to take part in the survey. Verbal consent was considered appropriate for this sample because the questions in the survey were relatively non-intrusive. After the interview had been completed, women were offered an informative page on cervical cancer prevention and Pap smear benefits as a participation incentive. The data were analyzed using the Statistical Package for the Social Sciences (SPSS) version 10.1, by conducting descriptive statistics, paired t-test for comparison of means, and McNemar Chi-square for comparison of proportions. To examine the best predictors of intention for screening and screening behavior, multiple logistic regression analysis was conducted. The critical alpha value for statistical tests considered significant was  $\dot{\alpha} = 0,05$ .

#### 2.4.3. Semi-structured Interviews with Key Informants: Sample and Data Collection Methods

In order to contextualize women's beliefs, attitudes, behaviors and experiences with cervical cancer screening in a real life context, it is important to understand the organization of the health care system in Romania.

Six trained interviewers, four psychologists and two medical doctors (from Romanian Association of Health Psychology and Eastern European Institute for Reproductive Health, Targu-Mures) conducted interviews with policy, planning and clinical expert key informants. After the first four interviews, a review of the quality and comprehensiveness of the questionnaires was undertaken, leading to some adjustments in the instrument. The guide was used rather flexibly, depending on the professional role and position of the respondent and the interviewer had the freedom to probe for more information and explore tangential areas if they emerged.

We contacted 30 *key informants* in order to discuss the key issues of legislation and regulatory framework, funding sources, system capacity, the priority of cervical cancer screening among other health priorities, barriers and opportunities for change. Respondents included policy makers involved in developing policies on cervical cancer, leading oncologists and gynecologists, experts in public health, heads of cytology labs, the Health Insurance Fund directors, non-governmental organizations, members of the District Division of Health Care and Management of the Romanian Cancer Society, and other stakeholders. Interviews were conducted in a conversational manner, lasting between 20 and 40 minutes. Three key informants agreed to be interviewed only by telephone due to their time conflicting schedule.

# 2.4.4. Semi-structured Interviews with Health Care Providers: Sample and Data Collection Methods

We interviewed 50 *health care providers* and *laboratory personnel* in 9 major cities. The health care provider interviews focused on their experiences, knowledge, beliefs and attitudes towards screening programs while those with laboratory personnel focused on laboratory capacity (infrastructure and human resources), techniques and procedures, internal and external quality assurance, and needs for mass screening. The group of health care providers included family doctors (23), gynecologists (11 of whom 6 worked for the state, and 5 for private clinics and offices), oncologists (4), family planning doctors (5), epidemiologists (1), and cytologists (6). All the interviews were conducted face to face and they lasted between 30 and 70 minutes.

Three *focus group* discussions were conducted in Cluj, a city in western Romania: one group was formed of 5 family doctors; 6 family planning doctors and one gynecologist took part in the second group, and the third group comprised 5 nurses. The same topic guide was used but the discussions gave the opportunity for debate and validation of individual experience. The group discussions lasted 90 minutes on average.

Potential participants were initially contacted by fax or telephone, describing the aims of the study and asking to participate in a discussion either individually or in a group format, about their opinions, attitudes and recommendations for cervical cancer prevention. In the case of a favorable answer, doctors chose the time and place to be interviewed and all permitted the interview to be audio taped. Interviews were transcribed verbatim and data were analyzed thematically.

# PART III: FINDINGS

# 3.1. WOMEN'S PERSPECTIVE ON CERVICAL CANCER PREVENTION

In this section we discuss the main findings of the structured and semi structured interviews.

# 3.1.1. Study Group Characteristics

The socio-demographic characteristics of the survey sample (N=1053) are presented in Table 3. Participants ages ranged from 20 to 65 years old, with a mean value of 40.95 years. Most women were married (74.1%), and more than 50% had one or more children. A low educational level (primary and grammar school) was reported by 29% of women, a medium level (high school) by 47.2%, while 23.8% reported university level graduate and postgraduate studies. The nationality and religion of the subjects reflect the distribution in the general population (Romanian: 87.3%; Orthodox: 88.2%). More than half of the participants lived in urban areas (57%) while 43% lived in rural areas. 45.7% of women were employed, while the second category was comprised of: students, housewives, retirees, registered and unregistered unemployed women. Two thirds of the women (70%) described their family's financial situation as being neither prosperous nor precarious, while 19.4% considered that it fell in the poor and very poor categories. Only a minority of the respondents (10.7%) perceived their family's financial situation as being good or very good.

Age	%	Marital status	%	Number of children	%
20 – 29	25.1	Married/Cohabiting	74.1	None	47.1
30 – 49	44.9	Never married/single	13.5	One	33.1
50 – 65	30	Divorced/Separated	4.8	Тwo	11.1
		Widow	7.6	Three	1.2
				More than three	7.5
Education	%	Ethnicity	%	Religion	%
Low level	29	Romanian	87.3	Orthodox	88.2
Medium	47.2	Hungarian	5.5	Catholic	3.6
High	23.8	Roma	5.6	Protestant/neo-protestant	7.1
		Other	1.5	Other	1.1
Area of residence	%	Employment status	%	Financial situation	%
Urban	57	Yes	45.7	Very good	3.5
Rural	43	No	54.2	Good	7.2
				In between	70.0
				Poor	16.4
				Very poor	3

 Table 3. Socio-demographic characteristics of the sample (N=1053)

# 3.1.2. General Health, Well-Being, and Health Practices

Table 4 presents self-perceived health indicators, considered good mortality and morbidity predictors (Carlson, 1998). Life satisfaction, satisfaction with the family financial situation, along with high level of perceived control over personal life, are three other relevant dimensions of well being and health. A good or very good health status was reported by 41.6% of the women, while 19.5% evaluated their health status as being precarious or very precarious. More than half of the responders reported a medium satisfaction (neither satisfied nor dissatisfied) with life in general (55.5%) and with the economic status of their family (52.4%). A high level of life and financial satisfaction was indicated by a quarter of the women (25%), and by only 16% respectively. Despite a relatively low percentage of respondents declaring a high satisfaction with life and its economic dimension, almost half of the sample reported high or very high levels of freedom of decision-making and control in life. 11.6% of women perceived themselves as having limited or no possibility of making free and unconstrained decisions.

Dimensions	Very good/ very satisfied (%)	In between (%)	Very poor/ very unsatisfied (%)
Self-reported health	41.6	38.9	19.5
Life satisfaction	25.2	55.5	19.2
Satisfaction with financial situation	16	52.4	31.6
Perceived control over life	43.4	45.1	11.6

 Table 4. General health and well-being (N=1053)

A general feeling of well-being also indicates a certain degree of freedom of the pressures of every day life, as well as a higher openness towards positive attitudes regarding oneself. Health promotion behaviors are also included into this category. We further analyzed behavioral practices with a high relevance to illness prevention and health promotion. For example, the regular use of preventive medical services is considered a significant factor in promoting and maintaining population health, although as already reported, this has not in the past been encouraged by the Ministry of Health. In this context we were interested in the women's practice of taking general medical exams as well as in the periodical assessment of their reproductive health through regular gynecological exams. Results are presented in figures 4 and 5.



A quarter of the sample (24%) had not been to the doctor for a general assessment of their health status over the past 5 years, and the percentage was even higher (31.5%) in the case of gynecological exams. An approximately equal percentage of women (37.7% and 37.9% respectively)

reported having an annual general physical examination and a gynecological examination. A higher prevalence of annual check-ups among the more educated women was found. In the case of health problems, 93.4% of women reported that they turn to the GP or to a specialist in the public or private health sector for diagnosis and treatment. A minority (6.6%) declared that they treat themselves, ignore symptoms or turn to alternative treatment methods.

An illustrative result reflecting the accessibility and quality of gynecological services in state medical institutions (polyclinics) is the fact that 32% of respondents said they turn to private gynecological services, where the payment is done directly by the client to the person offering the medical service. Considering the fact that only 11% of the sample reported a medium monthly income of over 5 million lei (approximately US\$180), while 89% of the women reported monthly incomes below this figure, these data also indicate the extent to which women will go to access what they perceive as higher quality medical services in private gynecological practices.

In certain cultures the gender of the gynecologist can be perceived as a factor facilitating or inhibiting turning to his/her services. More than half of our sample (59.4%) had no preference in the gender of the gynecologist, 34.6% preferred women while only 6% preferred a male gynecologist.

#### 3.1.3. Cervical Screening History

To gauge the prevalence of cervical screening, respondents were asked whether they had "*ever had a cervical smear test?*" We assumed that some women could be uncertain about having or not having had a Pap smear, and therefore the interviewer briefly described what a cervical smear meant. Based upon description, the question was repeated. Only 4.5% of women reconsidered their answer: the percentage of women who had cervical screening increased by 1.2%, and the percentage of those who never received Pap smears also increased by 2.8%.



Our data document that Romanian women have a very low rate of participation in cervical screening programs. As Figure 6 shows, only 20.2% of our sample reported they had ever had a screening for cervical cancer; 73.3% admitted that they had never received a Pap smear, and 6.5% of women did not know if they had received one or not. These results are in line with results of previous research indicating a low percentage of women having receiving a smear test. Nevertheless, this figure is a slight increase over data from 1999, when 17% of women reported having had a smear test (Serbanescu, Morris & Marin, 2001).

Identifying socio-demographic variables associated with cervical cancer screening is a useful means of identifying groups with a high non-attendance risk. Therefore we compared the group of women who had had the test with the group of those who had never taken the test (Table 5).

SMEAR				Ē			
1691	Age between 20	29		30 / 40		Ano h	etween 50 / 65
Yes	11 0	23	23.7	307 43		Agen	22.9
No	89.0		76.3			77 1	
	00.0		$y^2 = 18.8$ (df=	=2. p<0.0	01)		
			MARITAL	STATUS	5		
	Married/cohabita	tion	Single		Divorc	ed	Widowed
Yes	22.2		9.2		32.0	)	13.8
No	77.8		90.8		68.0	)	86.3
			χ² = 19.06 (df	=3, p<0.0	01)		
	1	1	NATIONALITY/E		ROUP		1
	Romanian		Hungarian		Rom	а	Other
Yes	21.2		24.1		5.2		6.3
No	78.8		75.9		94.8	5	93.8
			$\chi^2 = 11.19$ (d)	t=3, p<0.0	J1)		
			RELIC	GION			
	Orthodox		Cath	nolic		Neo-protestant	
Yes	20.3		28	.9			18.9
No	79.7		71	.1			81.1
			χ² = 4.64 (d	f=3, p=0.2	2)		
			AREA OF R	ESIDENG	СЕ		
					Rura	1	
Yes		24.5				14.6	;
No		75.5				85.4	ŀ
			χ² = 15.88 (df	=1, p<0.0	01)		
			EDUCA				
Vee	Low Level		Mediun				High Level
No	90.0		23	.0 7 0			27.0
NO	90.0		$y^2 = 30.67 (df)$	-3 p<0.0	01)	l	12.2
			χ = 30.07 (u)	-3, p<0.0	01)		
			FINANCIAL	SITUATIO	ON		
	Very good	Good	Neither good	or bad	Poor	r	Very poor
Yes	22.2	38.7	20.2		14.7		9.7
No	77.8	61.3	79.8		85.3		90.3
			χ² = 21.12 (df	=4, p<0.0	01)		
			OCCUPATION		TUS		
	Employed		Re	tired			Unemployed
Yes	26.9		1	3.6			5.4
No	73.1		8	6.4			94.6
	$\chi^2 = 27.61 (df=2, p<0.001)$						

Tabla E	Socia dar	nographia	abaractariation	appapieted with	aaniaal	amoor (0/)
Table 5.	Socio-der	nourabnic	characteristics	associated with	cervical	sinear (%)

Results indicate that women over 30, with a higher educational level, married or divorced, residing in urban areas, employed, and having a good or very good financial situation and being a catholic, had a higher probability of having had a Pap smear. Roma women had the lowest screening attendance rates.

It is worth noting that there was a positive relation between behaviors promoting general health and screening behavior, as can be observed by looking at results in Table 6. Women with recent frequent use of physician services and those requesting annual general and gynecological examinations had a higher probability of also having had cervical cancer screening.

	Have you event	er had smear st?	K²	
		Yes (%)	No (%)	
	None	11.5	88.5	
How many times have	Once	19.3	80.7	
you been to a doctor in	been to a doctor in Between 2-5 times		71.1	
the last year?	Between 6-12 times	18.0	82.0	
	More than 12 times	17.4	82.6	28.71 (p <0.001)
	More than once a year	37.1	62.9	
llaw affara da waw ana fara	Once a year	30.1	69.9	
How offen do you go for a gynecological exam?	Once every 3-5 years	20.6	79.4	
	Less than once in 5 years	9.7	90.3	
	Don't know	7.8	92.2	70.24 (p < 0.001)

**Table 6.** The relation between health behavior and cervical smear

The dimensions of well-being (subjective perception of one's health, life satisfaction and feeling of control) were also significantly associated with having the Pap smear test (Table 7).

	Have you events test	er had smear st?	κ²	
		Yes (%)	No (%)	
How optiofied are you	Unsatisfied	11.9	88.1	
with your life?	Neutral	20.8	79.2	
with your me?	Very Satisfied	25.3	74.7	12.86 (p < 0.002)
How much freedom of	Unsatisfied	12.5	87.5	
choice and control you	Neutral	16.1	83.9	
feel you have?	Very Satisfied	26.4	73.6	20.28 (p < 0.001)
	Very Poor	16.7	83.3	
Self perceived health	Neither Good Nor Bad	18.1	81.9	
	Very Good	24.1	75.9	6.69 (p < 0.05)

**Table 7.** The relation between well-being and cervical smear

The satisfaction with life was negatively associated with the following barriers for having a Pap smear: the cost of the test (r = -.33 p < 0.01), too long travel to clinics (r = -.18 (p < 0.01) and long lines and waiting (r = -.11 (p < 0.01).

The mean scores difference for social support and perceived stress between women who had had smear test and those who had not, is significant, t = 4.19 (df=1050, p<0.001) for social support, and t = -3.82 (df=1050, p<0.001) for perceived stress. Our results reinforce the notion that the health screening behavior may be "psychosocial" in nature.

The effectiveness of a cervical cancer prevention program that uses an imperfect screening test, in reducing morbidity and mortality, depends on regular screening. According to national and

European regulations, a Pap smear should be repeated every 3 years (Linos & Riza, 2000). Thus, the very low percentage of women having had a Pap smear (20.2%) is even more worrying if we also consider the date of the last test (Figure 7). One third of these 213 respondents reported that they have smears at intervals longer than 5 years, or they take the test so seldom that they cannot mention a certain interval. On the other hand, 40.6% of women reported annual smears, which might be considered a waste of resources. Only 22.5% (or 4.6% of total respondents, n=1053) reported having smears at reasonable intervals.



Over 80% of the women who reported having had a Pap smear, said they were tested during gynecological exams requested either for specific gynecological problems (41.3%) (which is not considered "screening" per se), or as part of routine examinations (40.8%). It is surprising that such a low number of women mentioned family planning services as settings for getting a smear (0.5%), considering that 64% of the sample consists of reproductive age women, needing modern contraceptive methods. This result may indicate a low attendance of family planning clinics by many women in our sample (according to the National Reproductive Health Survey from 2001, only as many as 23% of women between 15-44 years of age use modern contraceptive methods; Serbanescu, Morris & Marin, 2001) or the fact that some family planning clinics may not offer them cervical cancer screening services.

When asked about who initiated the last Pap smear, half of the respondents mentioned the gynecologist, while GPs and nurses were mentioned in a surprisingly low number of cases (Figure 8).



In most cases, women stated that the doctor informed them that the Pap test had been performed. It is encouraging that 94.8% of women reported that they were informed of their test result. Most women reported asking for the result themselves, with less than 1/3 being informed by phone by medical professionals. Another positive aspect mentioned by Pap smear users was that 85.6% of them had the opportunity of discussing the result with the doctor.

We looked in more detail at the women with a positive Pap smear result. It is worth mentioning that of the 14.5% of women with a positive result on their last smear test, more than one third (34.6%) did not repeat the test, a finding that might be an indicator of insufficient information being given to clients about the significance of the result and the need for follow-up and monitoring. A positive Pap smear result was positively associated with unemployment ( $\varphi$ =0.18, p<0.001), Roma ethnicity ( $\varphi$ =0.11, p<0.05) and with a subjective perception of one's health status as precarious or very precarious ( $\varphi$ =0.07, p<0.05).

#### 3.1.4. Cervical Cancer and Cervical Screening Awareness and Knowledge

The decision to have a screening test should be based on informed choice, incorporating receipt of relevant knowledge about the purpose of the test and the procedure itself, and a verbal consent procedure. Correct information about the importance of a certain preventive behavior (the Pap smear in this case), is the first step towards the regular practice of that behavior. All respondents were asked if they had ever heard of the Pap smear (also called cytological test and/or test for the detection of cervical lesions by the interviewer). Survey findings were that awareness of Pap smears is low. As shown in Figure 9, approximately half of the women (46.3%) had never heard of the test before the interview. The very low rate of screening attendance is therefore not so surprising, as for a very large number of women non-attendance reflects lack of knowledge in this area.



An analysis of different aspects of needed information revealed that around half of the participants were not aware of the purpose of the test (48.1%), nor did they know that cervical cancer is a preventable form of cancer (46.8%); about one quarter of the women who had heard about it believed the test must be repeated every 6 months; the same proportion thought that the test should be requested only when symptoms appear. The level of knowledge about Pap smears was very limited in the subgroup of women that had not taken the test (Table 8). The statistically significant difference (p<0.01) between the knowledge scores (a mean of several questions) in the two groups (screened and not screened), leads us to conclude that a high level of knowledge is a relevant predictor of screening behavior. As expected, women's knowledge was found to be highly dependent on educational level (p<0.001).

Table 8. Knowledge about Pap smear

		Ν	Knowledge Mean score	Std. Deviation	
Have you ever had	Yes	213	4	1,60	
smear test?	No	840	1,90	1,85	
		t = 15.18 (df=1050, p<0.001)			

The survey also explored respondents' primary source of information about Pap smears. Mass media reportedly played the most important role in increasing women's awareness of Pap smear, the doctor/nurse being mentioned as the second source of information. Few respondents mentioned friends, family members and school as source of their knowledge.

#### 3.1.5. Women's Perceptions of Cervical Screening and Risk for Cervical Cancer

The need for knowledge about Pap smear and cervical cancer prevention emerged as a strong theme in qualitative interviews. Most women had incorrect information, whereas others indicated a need for information about who needed a Pap test, its frequency, and the benefits of having regular examinations. Some of our respondents believed that the test needed to be performed annually, others were convinced that the interval between Pap smears should not exceed six months, while a few of them stated that the test should be asked for when a woman has specific symptoms such as bleeding, discharge, or pain. Six women considered that Pap smears are unwarranted for menopausal women or the sexually inactive. For some of our respondents, the difference between Pap smears and vaginal smears were unclear, while other participants supposed that the test detected only cancerous cells. Only a few respondents understood the concept of pre-cancerous lesions. Most of the women did not see the Pap test as a test for health maintenance and disease prevention. Clearly some women did not understand the notion of asymptomatic illness; they believed that a smear test was appropriate only once symptoms were present:

I did not go to ask for the Pap smear because I can't have cancer. I'm feeling okay. Cancer is one of those diseases where you can't feel healthy.

I feel that nothing is wrong with me, so why should I have the test?

Women also proved to have a limited understanding of cervical cancer and misinformation about its causes. Stress, sexual misbehavior, bad diet, family history, pollution were among frequently mentioned risk factors for cervical cancer. The discourse of "dirtiness" as a risk factor also emerged from interviews. These misconceptions are illustrated by the following quotations:

I think that there is a minimum chance for me to develop cervical cancer because I have no risk factors: I have a healthy lifestyle, meaning that I don't smoke and I don't drink alcohol, I try to eat healthy and to avoid stress. It's true that the pollution and radiations after Chernobyl can also play a role in cervical cancer.

The lack of hygiene is a very important risk factor for cervical cancer. I also tell my little girl that you end up at the doctor if you don't take a bath every day.

Only one woman, with university degree and history of screening, mentioned the HPV virus as the main cause of cervical cancer. A few women did not seek a rational explanation for cervical cancer; rather they considered it to occur because of bad luck or fate, while others perceived a healthy diet as an efficient way of both preventing and treating a wide array of health problems:

Carrots are very healthy for cervical lesions. I have had lesions on my cervix, eaten carrots, and the doctor himself was surprised by how well I've recovered.

The interviews with women provided evidence of the absence of risk perception of this disease and the fact that testing is sought mainly when gynecological symptoms are present.

# 3.1.6. Psychological and Systemic Barriers to Access Cervical Screening

Although knowledge and awareness about cancer and screening are important, they are not sufficient factors for getting regular cervical smear. Objective and/or psychological barriers can come between the motivation to engage in a certain behavior and its actual completion. Potential barriers to regular screening behavior can relate to the medical system, to the doctor-patient relationship or to cognitive, motivational, attitudinal and emotional characteristics of the client. On investigating which barriers affected (or they perceive that might affect) the cervical screening behavior of our respondents, "My doctor never suggested it" (31.8%) and "Gynecological visits are unpleasant" (30.6%), were the most frequently cited from a list of 15 barriers (Table 9). Despite the fact that health professionals should assume a major role in promoting and maintaining health behaviors, and research indicates that women are more likely to attend the test when the doctor recommends it, our results indicate this does not happen in Romania. One third of women reported that had never been informed of the existence and importance of Pap smears by health professionals. Other causes of non-attendance, when asked what are some of the problems faced (or potentially faced) in obtaining a Pap smear, related to the health care system, were: "The high cost of the test" (25.5%), and "The long lines and waiting" (24.9%). To request a Pap smear, women must confront and overcome not only systemic barriers, but also subjective ones such as fear of being diagnosed with cancer, anxiety, embarrassment, a general state of exhaustion or the lack of time. One quarter of respondents reported that they would not go for screening for fear of a bad diagnosis: clearly health education needs to stress that attention should be given to informing women that cervical cancer is highly preventable if identified and treated in its early stages. As many as 16% of women considered that going to the doctor without having any health problems could lead to the refusal of being examined or to being labeled a hypochondriac (13.4%).

v ,	
Barriers	Frequency (%) (N=1053)
My doctor never suggested it	31.8
Gynecological visits are unpleasant	30.6
I fear a bad diagnosis	25.8
The costs of services and tests	25.5
Long lines and waiting	24.9
I don't think smears are necessary	18.2
I am too exhausted	16
I do not have time	15.9
Doctors do not want to examine me	15.9
Doctors might say I am complaining	13.4

Table 9. Barriers in obtaining Pap smears

A total "barriers" score was calculated by summing the answers to all 15 items on a scale from 1 to 5. The range of scores was from 15-75. The composite score relating to the barriers to screening noted by respondents was associated with the women's screening history (Table10). Women who had not had the test perceived significantly more barriers than those who had taken it (p<0.001).

i						
		Ν	Barriers Mean score	Std. Deviation		
Have you ever had	Yes	213	28.28	9.22		
smear test?	No	840	33.89	9.95		
		t = 7.45 (df=1050, p<0.001)				

Table IV. Perception of partiels to Pap silled	Table 10	. Perception	of barriers	to Pap	smears
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#### 3.1.7. Women's Perceptions of Health Services

During the qualitative interviews most women also indicated that they had never been informed about the Pap test by their family doctors. Cervical smear was not mentioned or offered, even to women who visited their doctors regularly for other health problems, as Maria stated:

I think I would take the test but no one has ever advised me to. I haven't heard of any of my friends or relatives having taken the test, and the GP has never talked to me about it.

As in the larger survey, women reiterated the fear of being diagnosed with cancer as a barrier in preventing them to ask for a Pap test. Cancer was considered to be a terminal illness: women felt that the early detection of cancer would not be useful, as the emotional turmoil from knowing that one has a fatal disease would only add more stress to the physical disease. Therefore, the fear of cancer led to the avoidance of thinking about cancer and preventive behavior:

I would go and take the Pap smear if I were convinced I am healthy, but I don't go, as I am afraid I could find out something bad. I prefer not knowing that there is something wrong with me.

Two women reported that the emotional cost of waiting for the Pap test result was high in terms of worry, anxiety and uncertainty. The potential for receiving bad news after taking the test contributes to women's resistance in requesting for a Pap smear, as one woman noted:

The three weeks until I got the result of the test that I had repeated were the most awful in my life. There was nothing I could enjoy any more.

In term of medical care, women perceive public services as being impersonal, and as lacking the necessary privacy and space for pelvic examination room. Some women disclosed their feelings of embarrassment and shame related to the procedure involved in gynecological exams, and how they felt "exposed" in front of a stranger, even if the doctor was a woman. A few respondents perceived male gynecologists as being more skilful, competent and professionally trustworthy than female gynecologists, while others stated their preference for a woman physician. However, the gynecologist gender discourse was not really visible in most women's accounts. Associated with embarrassment, women experienced a feeling of vulnerability and insecurity related to not knowing what to expect. Addressing such concerns by the doctor could relieve women's distress and increase satisfaction with care. Participants described their feelings and experiences:

I never go to the gynecologist because I am too embarrassed. It's probably carelessness as well, but mostly embarrassment. Money is not such a big issue; you can borrow it to pay the doctor if you don't have it, but embarrassment is the main reason that prevents me from going. Getting undressed in front of others, discussing issues that you don't even discuss with your husband, or friends, or anyone... How can you feel comfortable doing that with a stranger, even if he is a doctor?!

The gynecological exam is extremely unpleasant, getting undressed and exposing yourself on that horrible chair. It's a lot easier to go and have your blood pressure checked; you only have to put your arm on the table after having lifted your sleeve.

Women's stories of gynecological exams ranged along a continuum of experiences from mildly unpleasant to intensely stressful. A few women reported traumatic experiences related to gynecological exams, which led to an avoidance strategy around preventive reproductive health behavior. For many of the participants, the relationship with the provider appeared to play a critical role in whether they come back for medical care:

It's happened to me with a gynecologist from polyclinic – he was so brutal that the examination was a shock for me. I will never go back to them again as long as I live.

More than two thirds of the women were dissatisfied with the experience of care they had received in a public health facility. Distress and dissatisfaction with care were shaped by factors related to the health care system but also by the health care providers' attitude. Accessibility was a frequently occurring theme. Several women described having to wait long lines in order to get an appointment, the lack of the possibility of establishing phone contact, lost results, rude and unprofessional staff, depersonalisation of care. Other women indicated that the physician's consultation schedule was problematic for working women. Many women mentioned they would be more likely to go and request a Pap test, if the appointment with the doctor was easier to get:

Taking the test is complicated if you don't have the money to go to a private practice. You first have to queue at the GP for a referral. Then you have to go to the polyclinic early in the morning and queue again for getting a number to see the gynecologist. It may happen that all numbers are up by the time you get there. If you have managed to get a number, you can finally go and wait for hours in front of the door of the gynecologist's room, as there are always other people who don't mind the order. It's happened that the gynecologist left to a meeting right before my turn came. So it's possible to go once, twice or even three times without managing to see the doctor, and it's not like you can afford missing from the job for an entire morning.

A common theme in our participants' reports was that of most clinicians failing to realize that women needed to communicate with them and to take the time to explain things thoroughly. Physicians were criticized for not being open to answer questions, to take enough time to discuss health and treatment concerns with the patients. One woman said:

When you go to doctors you get the impression that you bother them, they give you an indifferent and superficial look, you are not given enough attention. You are treated on the verge of rudeness. They almost suggest that unless you are dying why in God's name you bother them, that your problem is not something they should be wasting their time with. Visits to the doctor have always left me with a bitter taste.

Women's concepts of ideal care during a visit to a doctor emphasized mutuality and interactive communication and exchange, compassion and sensitivity, respect and trust, but many consultations are far from this ideal. Gynecologists were perceived as arrogant, rushed and as not offering women opportunities to ask questions; they were viewed as lacking a more understanding attitude and a gentle behavior:

I believe that I have the right to be informed regarding the treatment, not that the doctor be irritated that I have the "guts" to ask about the side effects of the medication prescribed and tell me "Young lady, even an aspirin has side effects". I think I am entitled to a little bit more respect when I go to the doctor.

The theme of individualized care was pervasive. Participants emphasized the idea that each woman is different and that physicians should tailor communication to meet each woman's care and information needs. Because of feeling rushed, or perceiving doctors as distant and unapproachable, women reported being largely silent in their interaction with doctors. Some women used the factory metaphor to describe their experience of gynecological treatment in a state health care setting; other women described a feeling of alienation as they felt that the doctor "detached" their body from their mind and soul:

I am very disappointed by the Romanian health care system; doctors simply do not communicate with you. State gynecologists see 10 women in 15 minutes, like in a factory production line, while the private doctors spend 15-30 minutes talking to one patient. The ones in private practices are interested in communicating with you. This kind of behavior encourages the patient to go back to them.

I felt like a piece of meat in a butcher's shop when the gynecologist consulted me, without addressing me one word, as I was not there.

Respondents also expressed discontent and anger with the "*unwritten law*" of informal payments that a patient should give to health providers in state health care facilities:

Physicians are not interested in their patients, they want only money. Without money you cannot solve any medical problem. Medication for free is given only for doctor's friends and relatives.

You have to pay the state doctor. He expects you to give him money or a gift – he doesn't even give you a second look otherwise. Even when I went to state clinics, I didn't expect to be examined just for the sake of it, but at least they should treat you nice.

Women talked about a different experience and type of interaction with gynecologists in private settings: private practitioners spend more time with patients, answer questions, and empower women to make their own decisions. Users perceived private health services as having more personalized care and paying more attention to the woman in order to maintain her as a client, an a attitude helps women overcome embarrassment and inhibitions. Asking questions and initiating a dialogue were viewed as particularly important. Most women saw conversation as an opportunity to receive not only the needed care from the doctor, which included information, but also other components, including emotional support and reassurance. Involvement in the decision-making process was important for some women. They also talked about the friendly environment in private clinical settings, with music, paintings, flowers. Privacy during the procedure was seen as an integral element of private practices, and yet lacking in state health care facilities:

When you go to a private doctor he always listens to you patiently and with interest, he explains you what you need to understand. They are not the type of "state" doctors that give you a bored look as soon as you walk in the door. I prefer paying more in a private practice, and know that I am treated with respect, as a human being.

Romanian hospitals are horrible and so depressing, you have no privacy at all when you are being examined, people walk all around like in a train station. The way you are treated makes you lose faith in doctors and hospitals.

Thus, the woman-doctor relationship is an important factor that appears to facilitate or hinder women's access to Pap screening. Our results lead to the conclusion that screening attendance is affected by both factors related to the medical system as well as factors linked to the subjective reactivity of the woman. Screening promotion programs must therefore address both categories of inhibiting factors.

#### 3.1.8. Women's Beliefs about Cervical Cancer and Screening

Although it is generally assumed that information about risk factors and prevention of a disease lead to more effective health care, research suggests that knowledge is not enough to translate into practice. There are four other cognitive determinants of screening uptake that may be involved in making informed choices: beliefs related to health and illness, attitudes towards a specific test, perceived attitudes of others towards that test, and perceived own control over having the test. Consequently we looked at cognitive factors related with preventive behavior.

#### Health Beliefs

Beliefs about health and illness may be strong mediators between knowledge and behavior. According to the Health Belief Model (Rosenstock, 1990) human action is strongly influenced by perceived personal susceptibility to, perceived severity of a disease; and by perceived benefits and perceived costs of a preventive health action. Examining the mean health beliefs scores, calculated by summing the items score of each subscale, indicates that in general, our respondents did not perceive themselves as particularly susceptible to cervical cancer (Table 11). For example, only 9.5% believed that there is a high chance that they can get cervical cancer, while 32% believed that the probability is neither high nor low. At the same time, the mean score for perceived severity of the disease indicates that respondents were likely to perceive cervical cancer as a severe disease. Most of the respondents fell above the mid-point when assessing the benefits of cervical smears, meaning that Romanian women have a high confidence in the Pap smear. For example, 82% agreed or strongly agreed with the statement "I have a lot to gain by having regular smear tests". The mean score for perceived costs falls bellow the mid-point, indicating that respondents perceived less costs than benefits for having a smear test. Only 11% responded with a definitely yes, or yes to the statement "Getting a smear test is time consuming". Given the low number of women who have taken the test, these results can be also seen as contaminated by the tendency of women to give answers which are social desirable. However, a t-test comparison of the mean scores of those who have had screening and those who have never had the test shows that the two subgroups of women are different from the perspective of their perception of Pap smear costs and benefits.

			Ever had smear test	Never had smear test		
	Possible	Mid	(mean score, SD )	(mean score, SD)	t	Р
	Score	point	N=213	N=840		
Susceptibility	5 – 25	15	13.15 (4.04)	12.81 (3.89)	1.12	.259
Severity	4 – 20	12	13.74 (3.32)	14.20 (3.08)	-1.88	.060
Benefits	6 – 30	18	26.29 (3.71)	24.08 (3.79)	7.63	.000
Costs	6 – 30	18	10.87 (4.29)	14.43 (4.22)	-10.94	.000

 Table 11. Beliefs about cervical cancer and cervical smear

Women who have never had a Pap smear perceived the subjective costs of having a test as significantly higher (p<0.001), and the benefits as significantly lower (p<0.001). There were no statistically significant differences, however, in their assessment of their susceptibility to, and severity of the disease. These results lead us to conclude that these two components did not play a role in the decision to have, or not have, a smear.

#### Control Beliefs

A relevant cognitive construct related to health behavior is Health Locus of Control, developed by Wallston et al. (1978). Internal control refers to the belief that health outcomes are determined by own's actions and decision. Control by powerful other refers to the belief that the actions of doctors/nurses determine health outcomes through recommendations, actions and medication they provide. Chance control refers to the belief that health and illness are largely a matter of fate or destiny. Each subscale has 6 items, and the options for answer are ranged from 1 (strongly disagree) to 5 (strongly agree). The mean score of internal health locus of control (belief that health outcomes are determined by own's actions and decision) is higher than the mean-score of the powerful others (belief that the actions of doctors/nurses determine health outcomes through recommendations, actions and medication they provide), and both are higher than that of the chance health locus of control (belief that health and illness are largely a matter of fate or destiny) These results (Table 12) indicate that chance is not perceived as an important factor in the health locus of control. However, the mean score for this variable is close to the mid-point. In other words, the role of chance in staying healthy or becoming ill was neither firmly downplayed nor affirmed by our respondents. None of the three subscales of the Health Locus of Control was related to screening history. No statistically significant health locus of control differences were noticed between the subgroups of women who had had and who had never had the test.

	Possible Score	Mid point	Ever had smear test N=213	Never had smear test N=840	t	q
		-	(mean score, SD)	(mean score, SD)		,
Internal Locus of Control	6 – 30	18	24.79 (5.22)	24.26 (4.27)	1.549	.12
Chance Locus of Control	6 – 30	18	17.8 (5.15)	18.57 (5.25)	-1.49	.14
Powerful Others Locus of Control	6 – 30	18	20.45 (4.22)	20.00 (4.7)	1.26	.2

Table 12. Health locus of control dimensions

As shown in section 3.1.3, screening history was significantly related to women's feelings of control over their lives (p<0.001). Perceived behavioral control and self-efficacy related to attending Pap smear within the following 3 months were evaluated by one item each, on a scale from 1 (no control/extremely difficult) to 5 (complete control/not at all difficult). Perceived control and self-efficacy reflect optimistic self-beliefs about being able to initiate and accomplish a specific behavior even in the face of obstacles or barriers (Bandura, 1997). Only 4% of women perceived that they could not exercise control over their decision to ask for a smear test. Overall, women in the study had rather high beliefs of self-efficacy and control over attending a cervical screening test in the following 3 months. However, self-efficacy and control were significantly associated (p<0.001) with screening history (Table 13).

Table 13. Perceived behavioral control & self-efficacy related to cervical smear

	Possible	Mid	Ever had smear test	Never had smear test		
	Score	point	N=213	N=840	t	р
			(mean score, SD)	(mean score, SD)		
Self-efficacy	1 - 5	3	4.34 (1.01)	3.8 (1.41)	6.32	.001
Perceived behavioral control	1 - 5	3	4.25 (1.01)	3.87 (1.16)	4.38	.001

# Normative Beliefs

There are a variety of reasons that can influence people to engage or to not engage in certain behaviors. People may be influenced by others or by their perceptions of what others think they should do. A number of researchers have shown that behavior can be induced by a normative component, termed *subjective norm* by Fishbein & Ajzen (1980). This component is represented by the person's perception of pressure from others to perform the behavior. Subjective norm was measured by two items on a 5-point scale ranged from 1 (strongly disagree) to 5 (strongly agree). The items were: "*Most people who are important to me would think I should go to have a cervical smear* "(injunctive component) and "*Most women who are important to me go to have cervical smears*" (descriptive norm). Our data reveal interesting findings. Overall, women's beliefs about what key people think they should do regarding having or not a Pap smear are around the mid-point (Table 14); these scores mean that women feel uncertain about other people's beliefs related to having or not having a Pap smear. Normative beliefs however, were significantly related to screening history (p<0.001). In other words, women who had had a Pap smear perceived a more encouraging attitude on the part of others compared to women who had never had a smear. Also, they believed that other important women in their lives were having this test as well.

Table 14. Normative beliefs					
	Possible	Mid	Ever had smear test	Never had smear test	
	Score	point	N=213	N=840	t
			(mean score, SD)	(mean score, SD)	
Injunctive normative beliefs	1 – 5	3	3,95 (1,07)	3,2 (1,22)	8,25
Descriptive normative beliefs	1 – 5	3	3,4 (1,12)	2,87 (1,06)	6,45

р

.001 .001

# Table 14. Normative beliefs

# 3.1.9. Attitudes Towards Screening

The process of decision-making reflects people's values and attitudes. To act in a specific direction requires that people behave in line with their motivation and attitudes. In other words, a decision also implies a positive attitude towards undertaking it. Therefore, we were interested in assessing women's attitudes towards asking the doctor for a Pap smear in the following 3 months, by using the semantic differential from the Theory of Planned Behavior. Most Romanian women reported that going to the doctor to get a smear test is an important, wise, safe, good and advantageous behavior on their part (Table 15).

Attending for a smear test in the next 3 months (%)								
Extremely important	Fairly important	In-between	Fairly unimportant	Extremely unimportant				
21.9	53.9	18.9	4.2	1.1				
Extremely beneficial	Fairly beneficial	In-between	Fairly harmful	Extremely harmful				
17.4	63.4	16.0	2.0	1.1				
Extremely wise	Fairly wise	In-between	Fairly foolish	Extremely foolish				
18.8	65.7	13.4	1.7	.4				
Extremely safe	Fairly safe	In-between	Fairly unsafe	Extremely unsafe				
16.8	59.1	19.6	4.0	.6				
Extremely good	Fairly good	In-between	Fairly bad	Extremely bad				
21.7	65.2	12.3	.4	.3				

The mean score above mid-point (which indicates an ambivalent attitude) shows that respondents had a rather positive attitude towards cervical smear (Table 16). The t-test was employed to compare women's attitudes towards future Pap smears among women who had had screening with those who had never been screened. Findings show that women who hade had a Pap smear had a much more positive attitude towards screening (p<0.001) compared to those who had never been screened.

Table 16	. Mean	scores	of a	attitude	towards	smear	test
1 4 5 1 5 1 5		000100	<b>U</b> 1 U	alling a a a	lowarao	onnoun	

	Possible	Mid	Ever had smear test	Never had smear test		
	Score	point	(mean score, SD)	(mean score, SD)	t	р
			N=213	N=840		
Attitude	5 – 25	15	20.83 (2.3)	19.55 (2.73)	6.29	.001

#### 3.1.10. Intentions for Cervical Screening

A large body of social and health psychological research indicates that positive attitudes do not always predict behavior. The discrepancy between positive attitudes towards screening and the actual use of screening among Romanian women confirms these conclusions, reflecting a deep attitude-behavior gap among our respondents. Research findings argue that behavior can be best predicted by a person's intentions to perform that behavior and behavioral intentions are proposed to be the proximate determinants of behavior (Sutton, 1998; Conner, Sheeran, Norman and Armitage, 2000). Screening intention was assessed by the item "*If given the chance, do you intend to attend for a smear test in the next 3 months*"? A high percentage of the Romanian women (77%) who did not get a Pap smear in the last 3 years stated that they intended to get one within the following three months

(Figure 10). Only 9% declared that they did not intend to get a test within the following 3 months, while 13.8% were undecided. However, the behavioral intention reported by the respondents does not reflect that the behavior will be certainly performed, but only the individual's estimation of the likelihood that she will perform a specified future behavior in a favorable circumstance.



## 3.1.11. Women's Constructions of Prevention

Although data obtained through the quantitative survey show that women have a positive attitude towards undertaking the Pap smear, qualitative interviews reveal a mixed and complex picture of how women conceptualize prevention. Generally, participants' accounts indicate that women seemed to theoretically value preventive care, but this attitude is not translated into practice. Most women expressed their willingness to defer medical checkups as long as they feel well. The doctor was constructed as a professional who deals only with disease and ill people, and health as feeling well and as the absence of symptoms. Women reported that the only time they would see a doctor was when they were really sick; few of them even proudly stated that they had never seen a doctor except for the childbearing months, as shown in the following excerpts:

I am not the type of woman who goes to the doctor for any little thing. You know the saying: the more seldom you go to the doctor, the better.

My body is resistant and it hasn't created me any problems so far, at 49, so I've never had to go to the doctor, except when I was pregnant.

Even though some women seemed to be aware of the need for regular medical check ups, this was not a health behavior they were actively pursuing. Therefore, women felt the need to legitimate their attitude. The issue of not having time to look after themselves, the daily hassles, the pressure of putting other's needs ahead of their own, the "*Romanian mentality*" of not reacting till "*the bell is ringing*" were among the reasons mentioned by women for not acting proactively to protect their health. The rationalization of this attitude translated into a health care avoidance strategy reflects the attempts of the person to make sense of this conflict situation and to reduce tension between what they think and what they actually do:

I don't even know my GP. I have registered with him but I've never been there. Although health should be the top priority we no longer pay attention to it because of all the stress in our lives.

I'm fine, and there is no reason for me to go to the doctor. Unfortunately this is our mentality: people only go to the doctor when they have problems, when something bothers them. As long as they are still standing everything if fine; when something starts going wrong, we start minding our health. We only go to the doctor when the bell rings.

Unrealistic optimism was also expressed by some women as a mean of confronting their worries related to health. Very few women expressed a fatalist perception of health and disease that might have explained their avoidance of self-care.

I don't want to hear about illness; on the other hand, I am an optimistic person and I convince myself that there is nothing wrong with me. My positive thinking and good luck has helped me through allot in life.

#### You cannot get away from what has been written for you, regardless of what you do!

The Pap smear was conceived by some respondents as a woman's problem, something which should be assumed among other women's responsibilities. Feeling responsible towards one's children reportedly activates in some women the "moral duty" to keep themselves healthy, and within this context, they reported such advantages of preventive medical examinations:

A woman should try to stay healthy first and foremost because of her children; you're also responsible to yourself, but mostly towards your children because they depend upon you.

Other women mentioned the possibility of a healthy lifestyle through physical exercise, diet, or having a personal doctor willing to offer his/her services at your home, as something only wealthy or women with a high social status could get, "those that are not daily confronted with the burden of an ordinary woman's life."

Since going to the doctor only when you are ill was constructed as a social norm, not following this norm appeared to generate apprehension that the others might perceive you as a "*person having problems*". Some women mentioned explicit negative reinforcements from others when they mentioned going to the doctor to get a cervical test or a general medical checkup.

"Are you obsessed with diseases or do you wish to live for ever?"

My mother has never taken the test, nor has she ever heard of it. When I told her I was going to take it she asked me why I needed to go to the doctor if there was nothing wrong with me; doctors always discover something to scare you and then put you into the hospital, which you never leave healthy.

Some young women expressed their concern of their doctors refusing them a general check-up, or of being considered a hypochondriac that takes up time, which should be devoted to people who are really ill:

As a young and healthy woman, I would feel really bad to take up the time of a doctor for a simple checkup, knowing that there are dozens of sick and old people waiting in front of his door in order to be seen and get treatment.

#### 3.1.12. Locating Responsibility for Prevention

Women's attitudes towards responsibility for screening were quite diverse. According to some participants, women should have the right to choose or refuse preventive health care. Others stated the need to be assertive in getting the information needed for preserving their health, while some mentioned the benefits of an encouraging attitude towards women on behalf of the health providers, through friendly letters of invitation and even gifts offered to them as a method of reinforcing preventive behavior. These were expressed through quotes such as the following:

Each woman does whatever she deems appropriate with her body.

It's everyone's responsibility to take care of her own health. If you don't take care of your own health, then who should?

Women are responsible to get as much information regarding their health as possible. They should not wait for someone to inform them, it's their duty to do this.

In order to get women interested in taking part in such screening programs, they should be rewarded by something small, such as cosmetics or a toy, as they've done in the breast cancer-screening program.

However, a few women suggested that it might be useful to make preventive medical exams, including Pap smears, compulsory. This measure would be justifiable, our respondents considered, because of the need to educate women "once and for all" to take responsibility for their health. It is surprising that some women explicitly expressed the opinion that since women tend to neglect their health, coercive measures are needed in order to make them have regular medical exams. Some went as far as suggesting that "punitive actions" should be taken against women ignoring preventive exams, an opinion reflected in the following quotations:

I think there should be a law coercing women to have annual medical exams; if they don't go they should lose their right of getting free medication and consultations. Otherwise, you know what women are like; they take care of everyone in the family but when it comes to their own health, they only go to the doctor if forced. This kind of attitudes leads to so many children growing up without a mother.

There should be some kind of a letter coercing you to go to the doctor to get the Pap smear; when you get that letter, you have to go, regardless of whether you want to or not. Women would go then. Otherwise it's difficult to find time for preventive medical exams. I know myself; I will not go and have the test out of my free will.

Despite the fact that visits to the gynecologist were not described in positive terms, all women were quite vocal in expressing their reluctance to have a Pap smear performed by a GP. The GP was perceived as not competent to deal with serious health problems, let alone gynecological ones. As women reported, people turn to the family doctor when they have flu, primarily to get prescription for free of charge medication, or referrals to the specialist. Even if GPs were specially trained to perform Pap smears, women would not perceive them as more competent than gynecologists, as several women stated. The idea that the gynecologist is the only trustworthy professional authority to manage cervical screening was a consensus among interviewed women. This attitude was expressed through quotes such as the following:

The Pap test should only be performed by the gynecologist; no way by the GP! The gynecologist spends 5 years specializing in that part of a woman's body. This is why he's called a specialist in the first place, while the GP is a "generalist" that is, he knows a little of everything. The GP is the contact person between you and specialists; he's the one who knows where to refer you.

I would never go to any other doctor for a Pap smear but to the gynecologist. Absolutely not! GPs should only perform the test in remote communities, where there are no specialists.

#### 3.1.13. Predictors of screening intention

Identifying these main predictors of screening intentions and behavior is important for the design of adequate health promotion programs. To identify the predictors of intent to be screened, data were processed with hierarchical linear regression analysis. The predictor variables were grouped into four blocks, based upon previous studies and theoretical models. The four blocks were added one by one to the regression model (Table 17). In this model, cases where the woman had had a smear in the past year (and who would not therefore need another smear in 3 months) were deleted.

state of health and medical	of Health	3. Components of Theory	4. Other psychosocial
history	Belief Model	of Planed Behavior	variables
AgeSetResidenceSuMarital StatusBetEducationCoEmploymentEmploymentFinancial situationReligiosityPerception of control over the lifeSatisfaction with the financialsituation of the familySatisfaction with lifeSelf perceived healthNumber of visits to GP during thelast yearThe last medical checkupErequency of gynecological example	everity susceptibility enefits costs	Injunctive normative beliefs (other's behavior example) Descriptive normative beliefs (perception of other's encouragement) Perceived self-control Self-efficacy Attitude toward smear test	Internal Locus of Control Chance Locus of Control Powerful Others Locus of Control Perceived stress Social support Barriers Knowledge

 Table 17. Variables included in regression analysis for screening intention

The results of the regression analysis for screening intention are presented in Table 18. Each of these models offers a prediction, but the third and the fourth are the most predictive, predicting nearly 54% of the variance. There are no significant statistically differences between the last two models, which means that variables added in the last model do not significantly improve prediction power. Consequently, model three was subjected to further analysis.

Model	R Square	Adjusted R Square	Chang	ge Statistics
			F Change	Sig. F Change
1	.080	.062	4.390	.000
2	.291	.273	52.454	.000
3	.537	.521	74.229	.000
4	.544	.524	1.649	.119

 Table 18. The results of the prediction models for screening intention

Table 19 shows the components of the regression equation, and the partial correlations (standardized and un-standardized value) for the third model (including only those variables that were statistically significant).

Table	19.	Regression	equation	components	of the	third	model
Iabic	13.	rtegression	cquation	componenta		umu	mouci

	Un-standardized Coefficients		Standardized Coefficients	t	р
Predictors	В	Std. Error	Beta		-
Age	008	.002	103	-3.331	.001
Frequency of gynecological exams	056	.026	063	-2.151	.032
Benefits	.026	.009	.099	2.975	.003
Costs	026	.008	110	-3.447	.001
Attitude toward smear test	.064	.012	.167	5.363	.001
Descriptive normative beliefs	.075	.027	.089	2.767	.006
Self-efficacy	.421	.028	.463	14.962	.001

The most important component of the regression model is self-confidence in asking for a smear test in the next 3 months; the value of its partial regression coefficient is 0.46. Negative coefficients signify that an increase in the predictor variable reduces the score on the criterion variable. A one-year increase in age decreases the intention for screening. The same is true for the cost variable; the intention rate simultaneously decreases as perception of cost increases. The gynecological exams variable is a reversed one: an increase in score on this variable means a decreased frequency of exams. Interpreted in this way, it is understandable why the calculated regression coefficient is negative: a low frequency of visits to the gynecologist (high score on this variable) is associated with a low score on intention.

## 3.1.14. Predictors of Screening Behavior

Because the past screening was measured on a nominal scale (Yes or No response) hierarchical logistic regression analysis was used to predict it. As in the case of the above presented linear regression analysis, the four blocks were added one by one to the regression model. Table 20 shows only the significant predictor variables included in the four blocks (significance was assessed with the Wald test).

	Ŷ	Į.			
	Model 1	Model 2	Model 3	Model 4	
Residence*	1.99 [1.28-3.11]	1.97 [1.23-3.15]	2.11 [1.30-3.41]	1.90 [1.13-3.20]	
Age	1.03 [1.01-1.05]	1.03 [1.01-1.06]	1.03 [1.01-1.05]	1.03 [1.00-1.05]	
Marital status (married)	.33 [.1571]	.34 [.1577]	.35 [.1583]	.35 [.1482]	
Education	1.60 [1.15-2.23]	1.47 [1.04-2.08]	1.54 [1.08-2.20]		
The last medical checkup	.77 [.6394]				
Frequency of gynecological	63 [ 51- 77]	646 [ 51- 80]	65 [ 52- 82	71 [ 56- 90]	
exams	.00[.0177]	.040 [.017.00]	201 201 001		
Susceptibility		1.06 [1.00-1.12]			
Costs		.86 [.8191]	.87 [.8293]	.88 [.8394]	
Descriptive normative beliefs			1.30 [1.03-1.64]		
Injunctive normative beliefs				1.27 [1-1.61]	
Knowledge				1.58 [1.37-1.83]	
Constant	.110	.130	.034	.94	
Nagelkerke R <sup>2</sup>	0.23	0.32	0.35	0.43	

**Table 20.** The predictors of screening behavior and the Nagelkerke R<sup>2</sup> for the four models

\* Residence and marital status were coded as dummy variables, the reference categories were Rural and Widowed; other variables included in the model were considered to be continuous

The explanatory power of the models increases progressively; the Nagelkerke R<sup>2</sup> coefficient indicates that the fourth model is the most predictive one for screening behavior, as it explains 43% of the variance of the criterion variable, meaning that this model has a good predictive power of screening behavior. Variables included in this model (selected from those included in the study, based on the Wald test) need to be considered as best predictors of screening behavior. Place of residence and knowledge about cervical screening and cervical cancer has the highest calculated odds ratio. The probability for a woman living in a town saying she will go for screening is 1.9 times higher than a woman living in a village since the odds of making a Pap smear test is 0.32 in urban and 0.17 in rural (see also Table 5). Each one point increase on the knowledge scale score, rises the probability of having a Pap test 1.58 times, while a one year increase in age rises this probability 1.03 times.

# 3.2. HEALTH PROFESSIONALS' PERCEPTIONS ON CERVICAL CANCER PREVENTION

This section covers findings of semi-structured interviews conducted with health care providers and key policy and planning informants.

#### 3.2.1. Cervical Cancer: Magnitude of the Problem

In order to take appropriate action in a given situation, it is necessary that the need is recognized and potential interventions are acknowledged. We were interested in finding out whether cervical cancer was perceived by health professionals as an important public health issue in Romania. The majority of our respondents (both key informants and health providers) stressed the fact that cervical cancer is a major health problem in Romania, expressed in the rising rates of morbidity and mortality. Only two health providers (both general practitioners) stated they did not consider that mortality rates due to cervical cancer had increased during the last years, but rather that data represent statistical artifacts, resulting from more recent improvements and transparency in recording of accurate data compared to the period before 1990.

Even though only few health professionals were able to accurately compare cervical cancer incidence and mortality with the Eastern Europe, most of them were aware of the high mortality levels compared to *Western* European countries. Out of the 30 key informants, and 50 health providers who were individually interviewed, only 9 mentioned Romania as having the highest cervical cancer mortality in Europe.

However, when discussing the priority of cervical cancer within the Ministry of Health, two thirds of the respondents expressed their belief that Romanian health authorities do not seem to perceive cervical cancer as a priority, given that no adequate prevention measures are being taken. Several other arguments were invoked to support this opinion. It was mentioned that cervical cancer control and prevention are given the same status as colon and prostate cancer prevention, although epidemiological data concerning the latter types of cancer are not as worrying as those for cervical cancer, and as cervical cancer precursors are much more easily detected.

The Ministry of Health is interested in the screening program as long as you don't ask for money. Their good will stops here. As soon as you ask for funds, they lose interest in screening and they no longer see cervical cancer mortality as a priority (gynecologist, chief of gynecology clinic).

The majority of respondents were critical of the way the Ministry of Health manages cervical cancer prevention expressing their belief that the response is very slow and inadequate considering the extent of the problem. Some health providers labeled the attitude of the managers within the Ministry of Health as being irresponsible and non-professional.

#### 3.2.2. Legal and Policy Framework

In order to reduce the incidence and mortality due to cervical cancer, the WHO recommends that cervical screening programs be planned within the national planning for cancer control (WHO, 2002). Official documents of the Romanian Ministry of Health and Family show that a national cervical cancer prevention and control program exists on paper (see section 1.3). We were interested in finding out if actors who could play a role in the prevention process were aware of the existence of the program, and of its legal and regulatory framework. We were also interested in documenting their opinions about these regulations, whether they are put into practice, and the way they are implemented.

The main finding of this section concerns the contradictory nature of the information offered by our respondents about the existence of a national cervical cancer prevention program in Romania. The informational gap does not appear only between key informants and health providers but also among key informants at different levels of management of health care system institutions. Some key informants, particularly the ones in top positions of the health management system, clearly knew about the existence of the National Program for Cancer Prevention and Control (*NPCPC*), legally supported by the Ministry of Health. Other key informants mentioned the fact that despite the existence of a legal

framework for a national strategy for cervical cancer prevention and control, the program is dysfunctional and invisible as it is not properly financially supported by the Ministry of Health.

The national cervical cancer screening program is one on paper rather than a real one. The Ministry of Health maintains it exists and that it is financially sustained, but this is not the case; that's the reason why we detect so many cases of stage III and IV cervical cancer. Without an adequate financial support, it is unlikely that such a program will be efficient and have visible positive effects (gynecologist).

I don't know about any national screening program. Women come to ask for the test at their own initiative, as the information level is higher compared to the former period, and because they are finally beginning to understand that it's good for them to have the test, but there is nothing formally organized (private gynecologist).

Several interviewees emphasized the fact that an urgent legislative change is needed, specifically that cervical cancer screening should be financed by the National Health Insurance Fund in order to implement an active screening at the population level. At present, screening is offered free of charge only to women within the screening pilot programs whether or not they are covered by the social security system.

Having a program on paper has no efficiency whatsoever if no necessary financial resources are ensured for the identification, mobilization and counseling of the women, and for taking the samples, preparing them and interpreting the results. Each of these sequences requires serious funding, not only talking (family doctor).

Some key informants at local levels stated that there is no real national program addressing cervical cancer prevention and that legal norms are just on paper.

Unfortunately there is no cervical cancer screening program in Romania, although in the clinic we do the test to all pregnant and admitted women. The medical staff in the clinic could be involved in mass screening if family doctors would mobilize women and send them to us, and if the costs would be covered by health insurance funds. We believe that it is our professional and moral duty to do this, but it seems that the Ministry of Health does not endorse this opinion (gynecologist, chief of a university clinic).

Health care providers' opinions were even more diverse than those of key informants. Most providers were unaware of the existence of the NPCPC. Out of the 50 health providers interviewed, only six mentioned the fact that a national screening program exists, referring to Ministry of Health documents, three that the program exists but that it is ineffective due to financial reasons, and two that the program only exists in name only. On the other hand, four providers reported having heard of the program, but having no supplementary information about it, 14 reported not being aware of the existence of a NPCPC, whereas 21 said that there was no such program in Romania.

What national screening program could there be? With whom and what? We only have one qualified biologist for reading Pap smears in our county (gynecologist).

A national screening program exists, at least on paper, and is coordinated by oncology institutes throughout the country. But the impact of this program is extremely vague in the local medical networks, and almost inexistent for women (gynecologist).

Our results indicate the need to better inform health care providers about the national cervical cancer control and screening strategy. Considering the fact that many of them are not aware of the NPCPC, the low percentage of women hearing about or benefiting from the Pap smears is not surprising. However, practically all health professionals were in favor of a national cervical cancer prevention program through active screening.

#### 3.2.3. Financing Cervical Cancer Prevention and Treatment

All our respondents said that the budget of the NPCPC was too low and fluctuating, and that financing sources (internal and external) were too uncertain to allow the development of a long-term, viable program to the national level. Women are offered a free Pap smear once every three years only in counties included in the screening pilot programs of the Ministry of Health. However, even in these model counties , such as the county of Cluj, financial resources restrict its reach. As one key informant stated, if the budget for screening is kept at the same level as in 2000-2001 and 2002-2003, more than 10 years will be needed to screen the entire target population once (the female population aged 25-65 in Cluj county is approximately 192,000, while financial resources cover the testing of 15,000 women annually). The other counties were allocated financial resources covering only 2,000 tests per county (in the year 2001 the female population of Romania, within the 25-64 years age range, was of 5,951,962).

According to the majority of our respondents, as long as reasonable financial resources are not provided, the National Strategy for Cervical Cancer prevention will only continue to function at the most at local levels (a few counties), and the decrease of cervical cancer mortality at national level will be insignificant.

There were health providers who believed that the Ministry of Health is doing a bad job managing even the existing financial resources. In the spirit of a poorly understood equality, the budget is distributed among counties included in the screening program, without actual needs and former activity being taken into consideration, as one key informant noted.

The Ministry of Health keeps distributing the money according to the communist logic. They are not interested in the actual size of the target population in a specific county, in the number of doctors and labs that sustain screening, and in their previous activity. Because the budget and materials have been divided equally, we're in the absurd situation of resources covering less than 30% of the demand in some counties, whereas in other counties the money has not been spent and materials have not been used (gynecologist).

The Ministry of Health has estimated an average cost of 350,000 Lei per Pap smear (about US\$12) that includes taking the sample and the analysis of the swab. GPs within pilot programs are paid by the Ministry of Health about 100,000 Lei (about US\$4) for identifying eligible women and taking the sample. If the GP does not take the smear, but refers the woman to another physician, he/she is paid approximately one US dollar. Health providers estimate that the amount they are given is insufficient for stimulating them to get involved in prevention activities:

Out of the 100,000 Lei, (US\$4), I pay approximately 30% tax; then there are also electricity costs related to the valve sterilizer and to other materials. In the end I am left with about 50,000 Lei (less than US\$2). Do you believe it's worth investing all that effort in looking up all women aged 25-60 registered on my patient list, convincing them to come to my office, changing my usual consultation schedule to set up the office, taking the samples, carrying them to the lab and going to get the results, calling up the women at home, as many of them don't return for the results? All this for 50,000 Lei! I believe that the goal of the Ministry of Health is nothing but to humiliate us once more. I do all these things only for the satisfaction of helping women (family doctor).

The lack of interest by the Ministry of Health in the screening program was also inferred by several providers from the fact that there are usually long delays in payments for cervical screening activities. These management problems generate dissatisfaction among health providers. Participants suggested that a more attractive financial incentive for screening activities would stimulate more GPs to do the screening themselves:

I was on the point of giving up getting involved in taking smears when, after mobilizing many women, the ones responsible did not provide us with the materials needed and the financial compensation. But it so happened that the same week I got the result of a 36 years old woman diagnosed with stage II cervical

cancer. Then I told myself that I couldn't give up, regardless of the conditions that we are forced to work in. Women are not responsible for this situation. If I had not taken smears last month, a young life would have probably been lost (family doctor).

During the hours that I spend mobilizing for screening and taking samples, I could pay home visits to patients that are financially rewarded both by the patient and by the National House for Health Insurance. I often vacillate between continuing with this philanthropic work in a situation where the ones that should be interested are not, and taking care of my family's financial interests, as many doctors do. Why do you think there are so few family doctors that agree to get involved in screening activities?! But I am not that kind of doctor! (family doctor).

GPs who got involved in the cervical screening program perceive this activity as a moral duty towards women's health, and less as a professional duty, since it is not part of their contract with the National House for Health Insurance (NHHI) and/or Ministry of Health. Other family doctors, who refused to get involved in screening program, clearly stated that the lack of financial incentives made them take this decision.

When there is no money you lose all your enthusiasm regarding work, and I believe this is normal. Everyone works for money, so why should family doctors be different? We need to make a living too (family doctor).

The National House for Health Insurance only reimburses Pap smears that are taken by a gynecologist and when there is a suspicion of a pathologic condition. This attitude once more reinforces the curative dimensions of the Romanian health system. Some health providers (gynecologists and GPs) mentioned that in situations when a woman needs a test sooner than 3 years, or does not know where to go for a free test, they sometimes fabricate some pathology to help her get the test.

Gynecologists are not very interested in contracting with the screening program; the amount allocated within the program for one smear is much lower than half the price of an abortion (oncologist).

In cases where further investigations (e.g. colposcopy, biopsy) and cancer care are needed, these services are financed by the NHHI, provided that the woman is insured. One key informant, representative of the National House for Health Insurance at county level, clearly indicated that the role of the institutions they run is not, and should not be prevention but covering the costs of diagnostic and treatment procedures.

"We all know that preventing is better that treating, but you must understand that prevention is not part of our attributions. There are other institutions that should assume this role".

Key informants' and health providers' opinions regarding the responsibility of financing the screening program were divided. Some of them reported that they believe that the Ministry of Health is responsible for supporting the program out of government funds. All screening costs should be covered out of the budget allocated by the government to the health sector, so that women are offered these health prevention services for free, according to the regulations established by the Ministry of Health. *"It is the role of the state to be concerned with the health of the population"*, a GP noted. Others reportedly appreciate that the NHHI should assume this role, considering the fact that although prevention is costly, it is nevertheless more cost-effective than treatment:

The NHHI has the duty of covering screening, and more than that: it should pay for keeping the population informed concerning these aspects. The National House for Health Insurance does not fulfill its attributions so the Ministry of Health should sanction this by taking some of the funds that go to them from people who pay health insurance (family doctor).

Key informants representing national professional societies (of oncology, gynecology) noted that it is the duty of each professional category involved in cervical screening to get external funding through viable and cost-effective projects.

However, there were also voices maintaining that considering the significant financial deficit of the Romanian medical system, and the fact that vital treatment and medication cannot be provided to patients with chronic conditions, the responsibility of illness prevention should be shared by the population:

Women should be educated to understand that it is important for them to be tested regularly. A Pap test is not more expensive than 5-4 packs of cigarettes. The difference is that by smoking she increases her cancer risk, while by requesting the test she reduces it. Of course, each person has the right of choosing, but they should be educated in order to know what to choose (gynecologist).

A woman is willing to pay probably the double of what a Pap test costs to get her hair done. But this is what Romanian women are like: as long as they don't have any health problems, they are more concerned about the way they look on the outside than about what goes on inside of their body (gynecologist).

The cost of the Pap test in private facilities varies between US\$5-12, to which the cost of the gynecological exam is added. Although gynecologist evaluate this cost as being under the real one, some admit that many women cannot afford it, and that the Ministry of Health should take urgent measures to ensure free Pap smears to all women.

#### 3.2.4. Practice Regulations: Target Groups and Interval for Screening

The World Health Organization (WHO) has established that the target population for cervical screening should be defined in terms of age and history of screening (WHO, 2002).

To have an impact on cervical cancer incidence and mortality, a new cervical prevention program with limited resources must achieve minimal goals such as screening all women aged 30 to 50 at least once before expanding services to other age groups. The reason for this is that in younger age groups most HPV infections and low grade lesions are transitory and will regress spontaneously: treatment of these women will likely be unnecessary. Also any lesions that do progress, will progress slowly, giving ample time for treatment after tests later in life. In women over 50, it is likely that any lesions identified will be advanced and impossible to treat. However, between the ages of 30-50 is the period when there is a peak of high grade lesions – lesions that must be treated or they will likely progress, but also lesions that are highly receptive to treatment. By focusing on these groups, limited health funds will concentrate on where most disease reduction will be achieved. If resources are high, and a large proportion of the target group is being screened, screening should be extended, first to older women (up to the age of 60) and then to younger women (down to the age of 25). Section 1.3 describes the selection criteria of the target population in Romania and the interval considered optimal for screening.

Interviews indicated that the majority of health providers are unaware both of international guidelines and national regulations. Some admitted not being familiar with the methodological norms of the Ministry of Health, while others, particularly gynecologists, stated they did not need to know the Ministry of Health protocol as they guide their activity according to the international literature in the field:

Yes, there are formal norms, but we don't have them; as I have already said, in our case screening is practiced on an opportunistic basis. Other countries have norms regarding the interval of scheduling women for Pap screening, but we don't have them (family doctor).

We don't have any regulations regarding screening. I know from the literature and from health policies of other countries that screening is practiced according to age: once every 3 years for women over 30 years of age, and once a year for women over 40 years of age (gynecologist).

Let's be serious?! What good are all those protocols and regulations? We know all too well what we have to do. On the one hand, we've learned these things when we specialized as gynecologists; on the other hand we keep ourselves constantly informed by reading articles in the field (gynecologist).

Nevertheless, the optimal age and intervals for cervical screening mentioned by gynecologists was quite diverse. Some noted that screening should be started at the beginning of sexual life and continue as long as the woman is sexually active. Others reported that all women over 20 years of age and up to 70 years of age should be screened, while 6 GPs suggested that women of reproductive age should be the target group of screening.

One gynecologist mentioned being happy to offer the test to as many university students as possible, since targeting this population, of 18-23 years of age, is beneficial for at least two reasons: first, the early detection of possible problems, and second, these women will learn to request the Pap test periodically for the rest of their lives.

The diversity of answers regarding target groups is not accidental, as pilot programs conducted in the country so far within the NPCPC have had different target groups and populations. Key informants reported that pilot screening programs conducted in different counties included women of different ages: 18-80 years of age in lasi county, 25-65 years of age in Cluj, while in other counties the target population was between 35-50 years of age, or 35-69 years of age. The target population for screening within the pilot program run by the Bucharest Oncology Institute was women between 18-80 years of age.

There are no regulations regarding this. Since there is no national program, everyone does whatever they feel like doing on their program; this is how medicine is practiced in Romania at present (family doctor).

Regarding the priority that should be given to certain risk groups, some health providers mentioned women with multiple sexual partners, promiscuous women, or women with an early debut of sexual life. Several health providers were concerned about women who seldom utilize gynecological services, namely women in rural areas, and women belonging to the Roma community. In addition, some providers mentioned that women older that 50 years of age stop requesting gynecological exams, as they tend to believe they have no gynecological problems once they get passed reproductive age.

The minimum and maximum age interval that screening should address, were hot topics during the focus group discussion, without a common conclusion being reached. International recommendations on screening intervals suggest that in countries where resources are limited, each woman should be screened once in her lifetime, at about 40 years of age. If resources are available, the frequency of screening should be increased to once every 10 years, and once every five years for women aged 35 to 55. If additional resources are available, and a large proportion of the target group is being screened every 5 years, the frequency of screening should be increased to once every 3 years for women aged 25-60 (Alliance for Cervical Cancer Prevention, 2004).

There were contradictory views about the optimal screening interval among interview participants. Most of our respondents mentioned that screening should be ideally conducted once every year. They invoked the fact that screening is also conducted annually in developed countries within the EU (although this is not in fact the case – some countries in the EU only screen every 5 years). However, some of them stated that given the limited resources in Romania, it would be unrealistic to have a similar objective to that of developed countries; some of the GPs and gynecologists involved in the pilot programs. Mentioned that 3 years would be the the optimal interval. Nine health providers (family doctors) reported that the Pap test should be done every 6 months. Only 4 providers (all gynecologists) mentioned that the screening interval could be increased to 5 years to allow for the possibility of screening more women in the country, a strategy that that would lead to a decrease in cervical cancer incidence and mortality.

Even though aware of the national norms regarding the 3 year screening interval, all private gynecologists that were interviewed mentioned suggesting patients to have the test annually. "*It's better to be safe then sorry!*", one said.

The test should be a part of the obligatory health program of any woman. Women should be tested twice a year, particularly if they belong to a certain age group or an enhanced risk group. Even an annual testing would be ok for the early detection of cervical lesions (family doctor).

The public health notion of screening *more* women, *less* frequently, was unfamiliar to most clinicians interviewed. A few key informants assessed having 80% of the 25-69 years of age female population screened every 3 years as an unrealistic short term goal, considering the budget provided by the Ministry of Health, and in a context where research indicates that at present, only about 20% of the female population in Romania has had a Pap test.

#### 3.2.5. Organization of Services and Clinical Practices

Interviews with key informants and health providers indicated that at present a national coherent and sustainable screening program does not exist. The first local active screening program was organized during 1998-2000 in the county of Cluj, and was extended to Bucharest in 2001. Both programs were financed with external donor resources. According to key informants, 87% of the women tested in the county of Cluj and 62% of those tested in Bucharest were having their first Pap smear. However, the population coverage achieved by these screening programs was low (around 28% in Cluj county). Almost half of the women tested by the Bucharest Oncology Institute were between 18-30 years of age (low risk women), and the lowest attendance rate was in the 51- 60 age group.

The first initiative of the Ministry of Health to organize, finance and implement active screening services was taken in 2002. During 2003 and 2004 the Ministry of Health financed, within the cervical cancer active prevention program, 1,000 Pap smears for each of the 11 counties included in the program (it must be noted that the female population aged 25-65 in the 42 counties of the country is of almost 6 million).

This active screening program is now operative in 11 counties but not at the level it should be. At the rate screening services are working now, it's absolutely certain that the goal of covering 80% of the target group will not be met, stated a manager of a screening pilot program.

Although, according to Ministry of Health regulations, smears are to be taken by GPs, and gynecologists are to be involved only where there are no trained GPs, most interviewed physicians indicated a totally different situation. They reported that most tests are taken on an opportunistic basis, during gynecological exams, prenatal consultations, or in the case of pathological complaints, as different gynecologists stated:

Asymptomatic women seldom come to the gynecologist. Pap smears are done in 80% of the cases to women who come for other problems. But if we take that opportunity to inform them regarding the benefits of the test, some of them tend to come back periodically. It will take a long time, however, before women will learn to ask for periodic preventive medical exams.

We cannot say that we have an active screening program; at the most we have a passive, opportunistic one. That is, no mass screening activities are conducted at present. Active identification means that you go to a factory, in a neighborhood or a village, and you test all women; this is what screening means. We stay in our offices – if women come to us, we offer them the opportunity of taking the test, but those who don't come to the gynecologist will probably never have the test.

Several key informants noted that nearly half of Pap tests continue to be done in private gynecological settings, suggesting that women with low financial resources have a high likelihood of not being

screened. A similar percentage of smears is taken in public gynecological settings (hospitals and clinics), while less than 10% of GP facilities in the country have reported to the Ministry of Health providing this service. In the county of Cluj, where regional screening activities are coordinated by the Oncology Institute, smears taken by GPs have exceeded 11% of all smears taken during June 2002-June 2004. Only 6% out of the 382 GPs in the rural and urban areas of the country have taken part in the screening program by actually taking smears, while an additional 10% have agreed to mobilize women, a key informant reported. Female physicians represent the majority of GPs involved in the screening program. Several key informants stated that there are no official norms that would make GPs participate in prevention activities.

It is worrying that the number of GPs who enrolled and signed service provision contracts in the screening program dropped to half in 2004 compared to 2003. One possible explanation for this is the lack of adequate financial incentives for doctors who take smears and/or the lack of mobilization of women for screening. There are also GPs who think they are not sufficiently trained to offer this kind of service while others believe Pap smears should be the gynecologists' responsibility, as they are overwhelmed by daily curative activities for their registered patients. Another obstacle mentioned by GPs was the necessity of setting up offices for this activity. Consequently, at most, some GPs reported taking smears only do this activity two days a week, at certain hours.

In this opportunistic screening system, respondents admitted that many women are inadvertently screened, thereby increasing the number of Pap smears performed, but not actually enhancing the coverage of the target population. A key informant reported, based upon an estimate conducted in counties throughout the country, that 2% of doctors test women every 6 months, 37% - annually, 17% - biannually, and only 12% perform screening according to the Ministry of Health regulations, namely every 3 years.

Discussions with key informants have revealed that not only the number of family doctors taking Pap smears is low, but also the number of those involved in mobilizing women for screening does not exceed one third of all GPs. In certain counties, women were mobilized through letters and personalized invitations addressed to those in the target group, which had not the expected result, as one key informant reported:

Unfortunately, out of the over 1,000 women that received letters, only a few over 100 came to benefit from free testing. It is clear to me that the female population that the letter was addressed to was not properly informed about the Pap smears.

GPs choosing not to be involved in taking smears have the right to refer the woman (if she is eligible for screening) to a physician accredited by the program, (either a gynecologist or another GP, according to the woman's choice).

Some of the gynecologists interviewed were resistant to the idea that GPs should be involved in smear taking, suggesting that their role should only be to inform and mobilize women. A few gynecologists expressed their approval with GPs conducting this prevention activity, mentioning that this would increase cost-effectiveness, but also expressing their concern regarding GP training.

I don't understand why GPs are so reluctant in sending women to have a gynecological exam; they believe they can fix all problems, and only send women in the advanced stages.

As a gynecologist working in the polyclinic it is quite difficult for me to perform screening activities. This place is crowded; we see a very diverse pathology. The GP is probably closer to the patients. It would probably be easier for them to have the smear taken by the family doctor, than being sent to the polyclinic gynecologist. This makes it more complicated for women. If the family doctor would learn to take the test, the detection of cervical cancer would become more efficient.

Nurses were rejected by most health providers as qualified personnel to take smears.

According to key informants and providers, *mobile* services for cervical and breast screening had been sporadically organized and conducted in rural areas of two counties (Cluj and lasi). The high rate of screening participation in these villages was emphasized, reaching levels as high as 98% of the target population (as the representative of Romanian Cancer Society mentioned).

Some key informants involved in the monitoring of screening programs mentioned that, particularly in the initial phase of GP involvement, the percentage of inadequate smears was higher than the established standard. The same key informants stated that over half of the providers still use the Giemsa staining method, although regulations require the use of the Papanicolaou staining method. However, some progress has been made, as one key informant noted:

The fact that the number of adequate smears taken by GPs has increased during the second and third year of pilot programs, confirms their potential role in the early detection of cervical lesions.

All providers reported that Pap smears, once taken and fixed, are labeled and prepared for being transported to the laboratory. According to providers interviewed, there are several methods used for labeling: some doctors write the identification data of the client and of the doctor/office on the slide, while others attach the reporting paper form to the slide. Both methods can prove problematic: in the first case, the writing can partially or totally be wiped off, while in the second case, the paper can detach from the glass slide. Providers have also reported that there is no organized transportation system to take smears to the labs. Many providers reported collecting all slides of one week, and sending them to the lab that they work with only once a week.

According to interviewees, the labs communicate smear results within 3 weeks. Some providers (GPs in smaller towns) reported usually getting the results within 4-5 weeks, and cases were mentioned (particularly during the summer holidays) when results returned within 2-3 months. Unlike providers in the public health sector, all gynecologists working in the private sector mentioned a 3-5 days interval for communicating results. There was confusion about results' reporting systems. Several key informants mentioned that the Papanicolaou system of classifying results was still widely used, although all interviewed cytologists (working in county labs) mentioned the Bethesda classification system. Ministry of Health representatives reported that the CIN classification was still temporarily being used, but that it would soon be completely dropped.

After the smear is read by the cytologists, the result is communicated to the doctor who has taken the smear. Women are instructed to go back to the doctor who took the smear to get their results. Health providers reported that not all women in the public medical sector return for their test results, unlike women who get the test in a private facility:

If they pay for the test, 99% of women come back for the results. I tell them what the test is about, and they are interested in knowing the result (gynecologist).

Respondents told us that if the smear is taken by the GP, it is his/her responsibility to contact and communicate the result to the women if they do not return for the result, and especially in the case of abnormal results. If the smear is taken by a gynecologist, he/she informs the GP through a medical letter, in case of normal and abnormal results.

The coordinators of pilot screening programs mentioned that in counties involved, 4-6% of the women screened were identified with dysplasia. Women in this situation are sent by the GP to the gynecologist where the second smear is reimbursed by the National Health Insurance Fund (because it is now deemed diagnostic). Following the gynecologist's recommendation, colposcopy, biopsy, conization or hysterectomy is performed.

Many providers emphasized the importance of screening, and supported this with the evidence that in counties where the program is being implemented, the detection of cervical carcinoma in early, curable stages doubled in 2003 compared to 2002. However, information gathered during interviews with providers, highlights the high rate of failure to follow-up women with invasive carcinoma or pre-cancerous lesions:

Out of 1,000 women that we have identified with dysplasia, approximately 100 returned for treatment; out of the 48 women identified with invasive carcinoma, for example, only 18 were treated by us; and out of 270 women identified with HSIL type lesions, only 60 returned to us. I am not necessarily implying that these women have not benefited from medical care, but we have not been able to get any information concerning these patients. This situation indicates the absence of a structure responsible for coordinating the follow-up of positive smears (oncologist).

Only a quarter of cases that need supervision have received the medical assistance required by the smear results within the first three months after detection (gynecologist).

Some providers described ways in which they try to be proactive in following up women and referring them for further management, while others mentioned barriers that they are confronted with in monitoring pathological cases:

I have had patients that I took by the hand and took to the Oncology Institute, after finding out that they had been sent from one place to another without being taken care of. However, I could only do this with women who came to me and complained about the absurdity of the situation (family doctor).

It is impossible for me to take the time to repeatedly call women who do not come to pick up their results, but have been detected with problems. We tell them to come back for their results, but if they decide not to, we cannot keep calling them all day long, when we see 40-50 patients daily. Moreover, using the phone is often restricted, as we exceeded the amount allocated for paying the phone bill (gynecologist).

However, due to the fact that women have the option of going to a specific gynecologist/oncologist and health facility, but also due to the fact that the information system does not function efficiently, the follow-up of pathological cases is often problematic. Some physicians perceived that emphasizing screening without increasing efforts of tracking down and treating women diagnosed with dysplasia, as being immoral:

I don't think it's ethical on our part and on the part of the medical system to inform women regarding cervical cancer risk, to mobilize them for coming to smears, to diagnose them with dysplasia or even cancer, and then not to have resources to focus our efforts on finalizing these cases, in situation they don't come to get treated out of various reasons (gynecologist).

According to respondents, colposcopy, cold knife-cone and hysterectomy are only performed in tertiary facilities and oncology units due to the fact that they can provide the equipment and necessary experience in performing these procedures. Colposcopy is also practiced in certain private gynecological facilities.

During 2004, the Ministry of Health funded 32,000 smear tests, three times as many as in 2003 (when only 11,000 were subsidized), but still much below the real requirements of the program. The most poorly covered areas are rural ones, where with very few exceptions of mobile-units services, screening does not really exist. Most respondents indicated that at present there is really no central management of the screening program, nor programs on the ground that would ensure the achievement of the stated goal of screening 80% of the target population. Among causes mentioned were the bureaucracy and complexity of administrative procedures associated with screening, lack of funding, and the difficulty of follow-up in cases of dysplasia. Several providers expressed their belief that the "chaos" in the screening program actually reflects the chaos in the medical system in general, generated by the frequent changes at the managerial level and by incoherent health policies that do not emphasize health prevention programs:

We need to change the orientation of screening in Romania, which is now preponderantly opportunistic, totally depending upon the initiative of the woman or of the physician, and does not properly cover the eligible population. We need an organized screening, namely an active one, based upon a database

containing eligible women, and upon a national and regional registry recording all screened women and their results (oncologist).

Extending the screening network to primary care is essential in order to ensure a vast coverage and the necessary infrastructure to conduct screening (county health promotion department's manager).

Some respondents suggested that before 1989 the screening program had a larger coverage as it used to be conducted at the work place, particularly in factories where most employees were women:

Years ago we used to have screening programs that were more efficient according to my opinion. Women working in factories were requested to come for oncological screening. It is true that screening programs were sometimes used as a means for detecting unwanted pregnancies. The pregnancy was officially recorded, and the woman could do nothing to get rid of it anymore, in case she did not want it. But cervical cancer detection was aimed as well (gynecologist).

#### 3.2.6. System Capacity: Infrastructure and Human Resources

Our study found that most Pap smears are taken in gynecological practices within clinics and hospitals, or in private clinics. At this secondary and tertiary level, where screening is mainly practiced on an opportunistic basis, providers reported that they had the necessary equipment in their facilities (brushes, slides, fixating agents etc.) to perform smear tests. However, gynecologists who have contracted with the institutions responsible for coordinating local screening pilot programs reported that it was common for them to run out of materials after the first few months of the program each year. Interviews with gynecologists indicated that not all of them had a colposcope.

Family doctors involved in the pilot screening programs were given gynecological tables, lamps, and the instruments necessary for taking smears (slides, Ayre spatulas, endocervical brushes). A small number of physicians reported using cervical brushes. Several GPs mentioned that they do not always have the appropriate materials for taking smears, or they mentioned inconsistency in the provision of supplies:

We have received speculums of one size only, that create problems in taking the smear in the case of some women.

Right now we are short of materials again, and this hinders our activity. Women come and ask about the test, they ask for an appointment, even come back several times, but they end up giving up as I cannot tell them how long the shortage of supplies will last. Some of them probably go to a private gynecologist to get tested, but I believe most of them give up on the idea.

Several key informants evaluated facilities in Romania as being minimally to well equipped, but also mentioned cases of poor use of the available equipment.

Some doctors have signed collaboration contracts within the screening program, requested the necessary equipment and materials, including computers for records, but at the end of the year it turned out that they had not taken any smears at all.

Two key informants revealed the fact that the financial and material resources allocated by the Ministry of Health are sufficient for only about 6 months. Insufficient funding leads to a bizarre situation, as one respondent labeled it:

On the one hand, our goal is to promote screening among the female population, while on the other hand we are forced to be "reserved" in informing and mobilizing women since we would not be able to cover the needs if all women in the target population asked for the test.

Due to the shortage of necessary supplies throughout the year, some programs only offer screening services at the beginning of the year, and focus on following-up and managing women detected with dysplasia during the second half of the year. The majority of cytologists use the conventional cytology and a low percentage of them mentioned using liquid-based cytology. Cytologists working in labs emphasized that the equipment is over 20 years old, and there is a need for binocular microscopes with more advanced optical and mechanical properties. Most cytologists reported that labs had the supplies and reagents necessary to process Pap smears. However, staff from two laboratories mentioned the poor quality of the reagents used, compromising the quality of smears. Other cytologists mentioned still having to deal with situations where they cannot read the results because slides are scratched, inadequately cleaned, and sometimes reused. Some labs have started modernizing their equipment but their activity continues to go on in the absence of skilled staff and national guidelines regarding practice.

We have the equipment, but we don't have the specialists who know how to use it (local representative of Ministry of Health).

Considering the adequate human resources in the Romanian health system described by key informants (8,300 GPs, approximately 1,100 gynecologists, about 16,500 nurses at the general practitioner level, and 4,000 obstetrics nurses), there appears to be no shortage of staff to do screening. However, according to key informants interviewed, the most serious cervical screening staffing issue is the low number of cytologists in Romania. Although there are one or two pathology labs in each county, there are counties with no pathologists. Currently, there are 323 pathologists in Romania, but few of them are involved in cytology. To become a specialist in cytology, pathologists receive specialized training including a laboratory-based internship. Even though the number of labs has increased during these last years, with private labs being open, the number of cytologists has remained the same, as staff have moved, at least for some of the working week, from the public to the private sector. In most cases the same lab staff work both in public and private settings. This situation is perceived by some key informants as being highly problematic as out of the few pathologists in the health system, not all are involved in cytological activities, and out of those performing cytological testing, not all have the necessary training.

Unfortunately, I must say that cytology is not of great interest for pathologists because it is considered to be neither profitable nor very attractive. Although cytology is part of the patho-anatomy training, it has been neglected in our country and has not been given the necessary importance. Only the truly dedicated ones of us have specialized in cytology (Lab chief).

Due to the low number of cytologists, biologists are also allowed to analyze smear tests, under the supervision of the head of the laboratory. However, cases of biologists working unsupervised in certain labs are quite common:

The biologist should and should not be involved in cytology. As a cytologist you should not limit yourself to reading and indicating the result of the smear, but also give further recommendations. This requires medical knowledge that biologists do not have. How can a biologist recommend a cold knife-cone or a biopsy?! And yet, there are many laboratories with only biologists, but I have my reservations concerning their competencies in some aspects of cytology. But considering the acute lack of cytologists, what can we do? (cytologist).

The case is the same with cyto-technicians who are not even included as a professional category in the Romanian professions catalogue. Because of the low number of cytologists, the cyto-technicians read over 1,000 slides a month in certain labs, exceeding the norms established by international guidelines.

We cannot have many cytologists in the system because of the high cost of their training, but what I don't understand is why we do not invest in training good cyto-technicians?! They could be of great help to cytologists, meaning they could do the triage of slides without any problem. Doctors could then focus only on pathological slides that need a diagnosis and further recommendations. This way doctors would be able to take all the time needed to read problematic slides. But we don't have cyto-technicians trained for this (cytologist).

Most key informants evaluated laboratory and qualified personnel resources as being insufficient for conducting a national screening program:

There are only few counties in the country that could support an extensive active screening program (chief gynecological clinic).

All physicians stated that at the time of their studies, the medical curricula included theoretical aspects of cervical cancer prevention, but no training in the practical aspects of it. There are no national structured training programs and curricula for doctors in screening, colposcopy, or treatment of precancer lesions. GPs involved in the screening program were offered training courses organized at local levels by oncology institutes. According to participants, these workshops did not provide adequate clinical training. Courses were evaluated by several participants as inadequate from a practical point of view, leading some of them to abandon the idea of taking up screening activities:

Training should have been longer and more consistent, including more detailed information. We were only given a brief theoretical background, and no details. Supervised practice was totally insufficient (family doctor).

Gynecologists and oncologists were trained in the diagnosis and treatment of cervical cancer through residency programs. However, problems in reading results in the Bethesda system were described even in the case of gynecologists:

The switch from the Papanicolaou reporting system to the Bethesda system is extremely problematic. We've started reporting results in the Bethesda system, and have had cases of gynecologist calling us because they did not know how to interpret lab results. We are far from speaking the same language, GPs, gynecologists, and cytologists (Lab head cytologist).

Courses in cytology have been offered during the past years by the professional society of cytologists and by NGOs in lasi, Cluj and Timisoara, but it is for the doctor to decide if he/she will take part in these continuous education courses. Furthermore training programs for cytologists are not standardized. According to the cytologists interviewed, pathologists choosing to become cytologists should participate in a 6-12 months postgraduate training program, and be accredited as cytologists only after reading at least 2,000 slides under supervision.

Discussions with key informants and laboratory staff have revealed that there is no formal training program for cyto-technicians, who get their qualification on the job, through supervision by the head of the lab. Two of the interviewed cytologists who have benefited from training outside the country, mentioned significant differences in how cytology is practiced in Romania and in developed European countries.

The training curriculum of GPs, gynecologists or oncologists does not include counseling information and skills. All health providers and program managers interviewed concurred about the need to receive refresher courses on cervical cancer prevention and treatment, patient information, education and communication, in order to be updated on the recent advances in the field.

#### 3.2.7. Information Systems for Cervical Cancer Prevention and Treatment

Interviews with key informants revealed the fact that there is no standardized information system for calling and re-calling women in the target age range for screening, or for recording

screening results and results of diagnostic and treatment procedures. Each medical unit records different types of data, and doctors and lab personnel have no obligation to follow a standard format for recording and reporting. The majority of providers noted that the recording of screened women is done manually into consultations logs or into individual consultation forms. A relatively small number of providers mentioned recording the names and data of women into computerized databases. They admitted that the information collected is often incomplete, the identification information on the referral note does not always match the one on the results, and situations appear when the result is given to someone other than the actual client from whom the smear was taken. Cases were also described when patients with positive test results could not be contacted because identification data were not correctly recorded.

Some respondents mentioned that until fairly recently women could pick up their results from the lab themselves. This way, there was practically no control over whether the woman would go back to her GP and have her result recorded, or be referred for a gynecological exam and further treatment. Clear measures have been taken in some counties in order for all the results to be directed to the GP or to the gynecologist that took the smear. Doctors involved in the screening activity are required to report all data related to screening to the center coordinating the activity. Gynecologists working in the private sector stated, however, that there are no regulations directing them to send the result of the patient to her GP. They suggested that it is the woman's responsibility to take the results from the gynecologist to her GP. Clearly there are many gaps in the way that information is recorded and shared between women, their GPs, the labs and the gynecologists. However, key informants described recent measures that have been taken to try to improve the cervical cancer program information system. Standardized forms for collecting data within the screening programs have been introduced in several counties. This new system involves a unique client form that accompanies the smear in the different phases of screening, diagnosis and treatment. The standardized form consists of identification information, clinical data, antecedents to testing, results from the accredited cytological lab and, when necessary, the diagnosis and treatment recommendations of the accredited gynecology or oncologyical gynecology facility, as well as the patient's progress, monitored by an accredited oncology center. Before this information system was set up, most patients were expected to keep their results that they would take (or not) to periodic exams.

Most key informants stressed the importance of developing an efficient information strategy that would involve the accurate recording of screened women, monitoring and follow-up of screening results, re-calling patients with positive test results, sending problem cases for diagnosis and the follow up of results and treatment procedures. Warning systems were proposed in the case of women with pathological results, in the form of colored marks on their medical records and individual health bulletins.

Discussions with lab directors provided descriptions of the way the information system works at this level:

The lab has to record each received sample into a daily record, which contains the name and registration number of the patient, and the name of the physician that made the referral. If major cytological abnormalities are observed, we also elaborate an interpretation report attached to the unique referral and reporting form. This interpretation report is elaborated by the director of the lab, and may be accompanied by recommendations regarding subsequent management. We also record on each form the name of the cytologist and cytotechnician examining the sample and elaborating the report.

Folders containing lab reports are kept for at least 5 years, and records of pathological results – for at least 20 years.

Discussions with key informants from the regional Institutes of Oncology provided information about their computerized information system. Some pilot regional reference centers now have computerized cytological records, containing information about the number of screened women, the number of re-called women, the follow-up of women with cytological abnormalities, and the monitoring of the regional screening programs. Among other roles, this system can facilitate the tracking of women with abnormal screening results, women diagnosed with cervical cancer being recorded into the Regional Cancer Registry of the Oncology Institute in Cluj or Bucharest, which have been connected to the European Cancer Registry since 1968.

These regional records have the advantage of being connected with territorial cancer records on the one hand, and with the County Health Insurance Fund database on the other hand, which offer information regarding the identity and address of women on GP lists (oncologist).

Physicians who are part of the pilot screening program are required to provide a monthly report of screening-related data (number of tests performed, number of abnormal results, number of referrals for colposcopy and biopsy) to the reference center that coordinates the program. These aggregate data are used for creating statistical reports for program managers and epidemiologists.

Respondents reported that there was no national population-based cancer registry, but rather two unlinked regional registries (Bucharest and Cluj). As one key informant noted:

In order for the cervical cancer prevention and control information system to be efficient, it is absolutely necessary for the Ministry of Health to develop the National Cancer Registry, that would be a preliminary condition for the national screening program.

The main obstacles in implementing and maintaining the information system identified by our respondents, have to do with the fact that many providers do not have computers in their facilities, and therefore they record the information on patients' individual forms; also not all providers use standardized referral and reporting forms; even when used, necessary data is often left out of the forms; regional cytological records are not being periodically updated.

#### 3.2.8. Quality assurance

The quality of the smear and its interpretation are key factors in ensuring the efficacy of a screening program. Findings from our study show that the issue of quality assurance is not regulated by national methodological norms. Local screening programs coordinated by the Cluj Oncology Institute and the Bucharest Oncology Institute have among their objectives assuring the quality of taking, interpreting and reporting smear results. Quality indicators have also been included as evaluation criteria in establishing the efficacy of pilot programs. A first quality assurance indicator mentioned by program managers was recording smear adequacy. In Cluj county, a key informant reported, the number of unsatisfactory smears taken by GPs has dropped significantly from 8% in 2002, to 1.14% in 2004, with an increase of limited quality smears to 16.46% in 2004. In the case of gynecologists, a 1% inadequacy rate was reported. According to the same person, inadequacy rates between 1.4 to 5% have been recorded among different cytology labs.

The number and proportion of false positive and false negative results is another way of evaluating quality. Only a few program managers mentioned the cyto-histological correlation as an important component of quality assurance in cytology labs. Within the pilot program conducted in the county of Cluj, the cyto-histological correlation was around 65%, comparable to international values. The proportion of women with confirmed positive test results who have completed subsequent diagnostic exams (colposcopy and biopsy), and undergone the necessary treatment within the established interval (3 months) was mentioned by program managers as a good indicator of program quality.

According to cytologists and key informants, there is no National Referral Laboratory in Romania, but this role is assumed by the laboratories of the Oncology Institutes in Cluj and Bucharest. The concept of accrediting cytology labs, as understood within the international community, is practically non-existent in Romania, as one key informant stated. Also the concepts of internal and external quality control are not widely used in Romania, because there are no national legal norms in this respect, according to several key informants.

Findings in our study indicate that reporting cytological results is based mostly on the personal experience and judgment of laboratory staff, without subsequent quality checking. External control was perceived by one lab respondent as a control method with punitive purposes. However, external

and internal control norms for lab activities have been established in some counties. According to cytologists, internal control consists of each positive slide being reevaluated by another member of the lab staff (in cases where there is more than one cytologist), with the final result being signed by both specialists. This procedure is not possible in labs where there is only one cytologist. A few labs practice external control of their activity by sending 10% of the slides to the cytological laboratories of the Cluj or Bucharest Oncology Institutes. According to few respondents, there is no quality control in most of the private sector laboratories:

Most private labs practice cytology by ear, and we cannot talk about a quality control of slide reading in Romania.

Due to major quality gaps between labs, one key informant noted that:

In Romania we can talk about cytology and "real cytology" in the true meaning of the word. There is a huge difference between these two types, and we should try to generalize the second one, if our aim is to have an efficient screening program.

#### 3.2.9. Information, education and communication

This section discusses the results of our study concerning the importance of who should be responsible for information, education and communication (IEC) activities in cervical cancer prevention. A prevention program (involving screening and treatment where necessary) is not effective unless it is known, liked and thus used by its target population, and as our results from the client interviews show, this is not the case in Romania. The main findings of this section concern the lack of agreement about the locus of responsibility between the main actors in cervical cancer prevention. . Most policy makers, gynecologists and oncologists considered offering information and educating as being mainly the responsibility of GPs, and that women should be made responsible for their health as well. On the other hand, GPs stated that they believe that it is the role of the media and informative materials prepared and distributed by the Ministry of Health to promote prevention activities, although they also stressed the individual responsibility in maintaining health.

As already shown in the section 3.1, the lack of information theme emerged in almost all interviews with women. The inadequate communication between the patient and the physician, limited to the "technical aspects" of diagnosis and treatment, generate, in most users, a perception of the medical system as being unfriendly and not oriented towards individual needs. The delegation of responsibility and abrogation of personal accountability for informing, educating and counseling among the actors involved in the health care system leads to a gap in the population's knowledge of cervical cancer prevention.

A significantly large number of providers perceived their role in providing information regarding cervical cancer prevention as being limited to explaining the Pap smear procedure to women. There is a common perception among physicians, however, that women do not understand the importance of preventive medical check-ups, because they are not properly educated to assume responsibility for their own health. In the meantime however, physicians do not consider that their "job description " involves educational activities:

We are clinicians, and by definition a clinician deals with medical problems, not with education and prevention; there is another health specialty dealing with these aspects within the medical curriculum: non-clinician health professionals.

The Ministry of Health fosters this attitude by not issuing any official regulation encouraging (or coercing) GPs to take up prevention activities. According to some health providers, women should be more responsible when it comes to their own health, and consequently be more proactive in asking for regular medical check-ups:

It is the individual responsibility of the woman to be interested regarding her own health. Forcing doctors to do this - go from house to house or to companies - is no use... Medicine would be compromised this way. It is women's responsibility to go to the doctor annually if they want to be healthy (family doctor).

Several health providers reported the shortage of information materials in health facilities, materials that should be developed by non-governmental medical associations:

If we had handouts and posters, we would place them on tables and walls in the waiting room. Patients could read these materials while waiting to see us, and they would learn more about cervical cancer. I don't think people would read these materials if they would be distributed elsewhere, because they are too preoccupied with other problems (family doctor).

#### 3.2.10. Health Providers' Perceptions of Women Responsibility for Prevention

A few gynecologists working in private facilities mentioned the changing of women's attitudes toward their own health:

Women's attitude has changed over the last decade. They come to the gynecologist at their own initiative now. At least 2-3 women walk into my office daily asking for a routine exam. There are few women who avoid getting the test. I explain them the benefits, and those who decide against it do so for financial reasons.

Other providers suggested that the main factor, hindering women's health seeking behavior is the socio-economic reality of life that imposes other priorities on women:

I believe it's the lack of interest of women concerning their health. In other countries, with higher educational levels, women are more concerned with their health. In our country, you know what things are like: the vast majority of the population has other, more vital, daily survival things on its mind, and health is left on the last place. Prevention is given no importance whatsoever, and women go to the doctor only when they have a problem. But you can't do prevention this way. Women should be educated that it is easier to prevent than to treat (gynecologist).

A few providers indicated that cultural influences, including the influence of men, should be taken into consideration when designing and conducting a cervical screening campaign. The situation of Roma women was brought up in this context:

Very few women request the Pap test at their own initiative; their low health cultural level prevents them from taking action in this respect.

Mobile units were set up, and we went to offer the test to all the women in certain Roma communities, but we only managed to convince few of them. Our health educator from that Roma community suggested that we should return another day, and that we should first go to the local pub and explain the men why their women should be tested. When we returned, almost all women in the village reported to our mobile unit.

Several gynecologists mentioned the embarrassment of some women, especially those with low educational levels or from rural areas, as another factor preventing them from having regular gynecological exams.

The issue of compulsion and penalty was raised by almost half of the providers interviewed, proposing sanctions for people refusing to attend general preventive exams. Several forms of punitive measures were mentioned: denial of insurance, fines, increases of the monthly insurance taxes, the requirement to pay for medical treatment if proven that the condition could have been avoided by preventive medical examinations. Many providers erroneously mentioned that western countries have adopted this kind of system. A few respondents suggested the idea of having certain incentives

introduced, such as financial bonuses, and the reduction of health insurance taxes for people attending regular medical check-ups:

Women should be thought to go to their GP for the early detection of several health problems. This could be done very easily, through insurance regulations. Let's say that women requesting preventive medical examinations could benefit from certain deductions of the fee they pay to the insurance company; they could be offered a 5% deduction for example, or they could be given a small amount of money as an incentive. They should be co-interested in the early detection, and I am sure they would come and get screened (family doctor).

This is the typical Romanian mentality, of putting off for tomorrow something that you could do today. Romanians do not think of the future if they are OK in the present. They only do this when confronted with a problem. I know that in other countries women that don't show up for screening cannot benefit from certain facilities offered by insurance companies. If Romanians would be educated the same way, I bet they would take better care of their health (gynecologist).

According to a quarter of the respondents, compulsory Pap screening when being hired on a new job would be another way of reducing cervical cancer mortality and morbidity. Some of them mentioned however, that many would be resistant to this as it would "bring up unpleasant memories from the compulsory gynecological testing period of Ceausescu, especially for women over 40 years of age" (gynecologist).

# PART IV: CONCLUSIONS AND RECOMMENDATIONS

# **4.1. CONCLUSIONS**

This study is one of the first attempts to understand the correlates of screening for cervical cancer in Romania, from the perspectives of both the beneficiaries and providers. The findings show that problems are multifactoral, and need urgent attention.

Romanian women have a positive attitude towards preventive health practices, although this is not translated into behaviors such as regular visits for medical checkups to the family doctor and gynecologist. This gap between attitude and behavior could be the outcome of historically-framed fear and dislike of the health system, and a medical system that emphasizes the curative dimension of health care, but also the effect of the daily stress and pressure women face, and of the social construction of health as the absence of symptoms. These results highlight the importance of educating women to have health check-ups in the absence of symptoms.

The prevalence of cervical screening among Romanian women is very low: only 20% of women aged 20-65 reported having had a cervical smear at least once in their life. Results reveal that there are substantial socio-demographic variations in Pap test screening. Those with lower education and financial resources, unemployed, residing in rural areas, single and/or widowed, and Roma women, were identified as underserved groups with regards to cervical screening. At the same time, results show that high education, satisfaction with life, perceived control, high social support and low social stress are related to screening behavior.

The awareness of the importance of periodic medical examinations in a segment of the feminine population indicates a possible positive attitude of these women towards practicing other preventive behaviors, such as Pap smears, as well. The recommendation of a Pap smear by the GP and/or by the gynecologist could undoubtedly become a key factor in these women's decision to adopt new preventive behaviors. The results reinforce the notion that health screening behavior is "psychosocial" in nature.

Knowledge appears to be one of the best predictors of screening behavior. However, findings reveal that awareness of the Pap smear is alarmingly low among Romanian women, as approximately half of them have never heard of it. Women who see a gynecologist regularly are more likely to learn about and to get the smear test. This can be regarded as the most important window of opportunity to educate women about Pap smears. Romanian women also appear to have a limited understanding of the causes of cervical cancer, which is constructed as a terminal illness with no hope for cure, even when detected in early stages. The need for information about Pap screening and cervical cancer prevention emerges as a strong issue from the results.

The perception of one's invulnerability can affect preventive behavior. Efforts to promote screening test uptake among women could focus on challenging beliefs of invulnerability to this disease. The counter-productive fatalistic attitude towards cancer and death should also be address through educational campaigns.

Women reported systemic and psychological barriers in getting the smear test. One third of women stated that they had not been informed of the existence and importance of Pap smears by health care providers. These results suggest that the under-use of cervical cancer screening may be due in part to a lack of physician recommendation. Other major barriers to cervical screening perceived by women include the high cost of the test, distress and dissatisfaction with the quality of health services, flawed communication with providers, anxiety produced by thinking about illness risks, and embarrassment and discomfort related to gynecological exams. Women who have not had the test perceive significantly more barriers than those who have taken it.

For many women, the benefits of cervical screening and early detection and treatment of precancerous lesions are far outweighed by objective and subjective obstacles encountered in the decision-making process of engaging in illness preventive behaviors. Encouragement to have a Pap smear by health care professionals in the context of a relationship built upon trust and respect is more likely to be heeded. Training interventions for enhancing medical staff communication and counseling skills could be one of the means of addressing barriers to cervical screening. The results also point to the urgent need for interventions that encourage health care providers to promote cervical cancer screening among less knowledgeable and to help reduce barriers that many women face in obtaining the smear test. Providing an acceptable screening service in terms of cost, time, accessibility should also be taken into consideration by health policy makers.

This study also provides insight into the important beliefs and attitudes of women with respect to cervical cancer and Pap smear. A significant proportion of Romanian women expressed a lack of sense of personal susceptibility to cervical cancer. Efforts to promote screening test uptake among women could focus on challenging the belief of invulnerability to this disease. Women do not express particularly negative beliefs about cervical smear; rather, once explained to them, they perceive it as an important, wise and safe preventive behavior. Women in the study had rather high beliefs of selfefficacy and control over the choice to be screened in the near future. Normative beliefs proved to be a significant mediator of screening behavior. The promotion of cervical screening activities should integrate these positive beliefs to overcome the barriers and psychological costs of screening.

The dominant discourse of: "I don't feel anything unusual, this means I am fine" could be read as a women minimization of prevention and health promotion behavior, as a result of the public policy of the former and present political regime. Another possible explanation could be a hierarchy of the woman's priorities according to the traditional model of "self-sacrifice", where the daily socio-economic hassles and the others' needs are the main priorities. In this context, women choose to adopt a denial and avoidance strategy concerning their health risks, up to the moment when symptoms cannot be denied. The avoidance of preventive care could be also interpreted as a form of resistance and passive protest against a depersonalized medical system, that pays attention to the curative dimension of an ill body, but ignores the patient's needs of human caring.

Information providing an accurate representation of the procedure may serve to make the experience more predictable and arouse less anticipated negative affect among non-screened women.

An encouraging result of the study is the high percentage of women declaring their intention to get a Pap smear in the following three months, if it was offered to them. Socio-demographic variables (age, residence, marital status, education), past behavior of medical checkups, knowledge about the Pap smear, beliefs regarding the psychological costs of the smear and susceptibility to cervical cancer, self-efficacy related to asking for this test, and subjective norms were the best predictors of intended screening behavior. As socio-demographic variables are difficult to change, knowledge of what the Pap smear is used for, as a strong determinant of screening behavior, indicates one of the main directions for improving cervical cancer prevention.

The low effectiveness of cervical screening programs in Romania is mainly due to factors associated with the unclear legal framework and regulations, poor program management and quality of health care system services and coverage. Romanian health policy-makers and health care providers recognize cervical cancer incidence and mortality as a major health problem and a national cervical screening program is unanimously seen as the best way to reduce the high rates of cervical cancer mortality. However, most providers do not perceive the response of the Romanian authorities as being adequate to address the magnitude of the problem.

Despite the existence of a legal framework for the National Program for Cancer Control, its reach is limited to a few counties. This situation is linked to insufficient funding by the Ministry of Health and to an incoherent strategy in approaching cervical cancer prevention and control. Most Pap smears are performed opportunistically by gynecologists, with the number of family doctors involved in this preventive strategy being very low. Cervical screening is not part of the national insurance health plan; smear costs are covered by health insurance funds only for diagnostic tests performed when pathology is suspected. Most providers advocate the need for legislative change, in the sense that cervical screening should be financed by the National Health Insurance Fund, as part of the primary health care service.

Many physicians are not aware of the existing regulatory framework and cervical cancer prevention implementation guidelines. This situation has led to substantial variations in practice with respect to target age groups, screening intervals, smears processing and reporting of results. Despite

the fact, that many countries adopted Bethesda system for rating the abnormal smears, some Romanian health institutions continue to use the Papanicolaou nomenclature, which is now obsolete. In addition to these problems, the Romanian screening program lacks epidemiological surveillance mechanisms that could guarantee follow-up and treatment of abnormalities detected.

Most general practitioners do not feel they have the appropriate training to perform smear tests. At the same time they feel there are no professional and/or financial incentives for them to be involved in any aspect of cervical cancer prevention. In fact, there are no official regulations that confer an obligation on family doctors to engage in prevention activities. These activities are perceived by physicians as being secondary to curative ones.

There is a general agreement among our respondents about the lack of sufficient infrastructure to support a national cervical screening program. The number of properly trained cytologists is far from being sufficient, the profession of cyto-technician is not officially recognized and labs lack modern equipment and technology.

Laboratory quality assurance is not regulated by national norms, the concept of cytology laboratory accreditation, as understood within the international community, is practically non-existent in Romania, and there is no national referral laboratory.

There is no standardized information system for calling and re-calling women in the target age range for screening, for recording screening results, and results of diagnostic and treatment procedures. Standardized forms for collecting data within the screening programs are only used in few counties. Family doctors do not have the means of collecting and updating the medical history of their patients. There is no an update National Cancer Registry, but only two unlinked regional registries. The quality and limited follow-up (reported by both providers and women) and treatment of diagnosed lesions, a serious limitation of the cervical cancer prevention and control program in Romania, may partly explain its ineffectiveness in reducing mortality rates. The importance of developing an efficient information strategy involving the accurate recording of screened women, monitoring and follow-up of screening results and treatment procedures was strongly emphasized.

The abrogation and passing of responsibility by all program stakeholders, for informing, educating and counseling women, has led to a gap in the population's knowledge about cervical screening prevention. Education of the general public about cervical cancer and its prevention is essential for encouraging health-promoting behaviors and reducing mortality from this disease.

There was no consensus among providers on whether smear tests should be obligatory or the woman's choice. Several ways to increase cervical screening attendance were proposed: from punitive measures to incentives and financial bonuses, and to empowering women to take informed decisions. However, without more effort expended on IEC activities, women will continue to be unable to make such decisions.

Several paradoxes emerged in the discourse of health providers. The first one is emphasizing the importance of preventive exams while stressing the priority given to the *truly sick* in their daily activities. With a few exceptions, represented mostly by doctors working in the private sector, it is clear that preventive activities consisting of check-ups are perceived by physicians as being secondary to curative ones.

The second paradox seems to be generated by the transitional social context, in which reminiscences of the old system intermingle with "important" elements from Western societies. In other words, the paternalistic and authoritative attitude towards women (the uneducated, irresponsible individual who needs to be coerced/ sanctioned to care for his/her health) coexists with emphasizing individual responsibility and self-agency in disease prevention These mixed attitudes and messages (even if not explicit), certainly contribute to the confusion of women regarding their role in assuming the protection and promotion of their own health. Many steps still need to be taken in Romania in the direction of the patient's right to being informed, and the patient's empowerment to make informed decisions.

The information presented in this study justifies an urgent need for interventions to reorganize cervical cancer screening in Romania through strategies for training providers, providing health care workers with incentives to undertake prevention activities, informing women about cervical cancer screening, increasing coverage, improving compliance, improving quality, and ensuring follow-up and

treatment for clients with abnormal test results. This study also suggests that Romania still has a long way to go before being able to achieve screening rates comparable to those from developed countries. Such efforts should include not only influencing awareness, knowledge and perception through public education, but also reducing barriers created by the health care system, and creating a new and appropriate environment for the delivery of this important health service. Policy and political will are necessary to reach these goals.

# 4.2. RECOMMENDATIONS

Improving the cervical cancer screening program in Romania requires a wide variety of activities, at different levels and by a multiplicity of actors. Apart from the health sector, other sectors of society have to be involved. We recommend the following strategies:

# 4.2.1. Policy recommendations Regulatory framework

- Improve protocols of National Norms, Regulations, and Procedures for the Detection and Control of Cervical Cancer, the protocols should be clearly defined in regulatory and policy documents and should reflect consensus on a screening policy between the Ministry of Health and professional associations.
- Develop strategies to disseminate the National Norms, Regulations and Procedures for the Detection and Control of Cervical Cancer in order to standardize screening and treatment activities. Develop advocacy strategies oriented toward decision makers to encourage them to develop relevant local and national strategies for cervical cancer prevention.

## Organization of services

- Policy measures should be undertaken in order to reduce barriers, which obstruct women's pathways in the health care system.
- Integrate smear tests with family doctor practice, family planning and reproductive health services; however, cervical cancer screening should also be integrated with other medical services that older women are more likely to access than reproductive health services. Introduce screening services in rural areas and use mobile units for taking smears in isolated areas.
- Adequate and constant financial resources should support cervical cancer screening policies. Reimbursement mechanisms should be clear and fair.
- > Introduce an incentive program for family doctors who agree to perform smear tests.
- Create linkages between public and private sector facilities in order to provide comprehensive prevention and treatment services for cervical cancer.
- Develop strategies to improve the referral and counter-referral system within the public health sector.
- Research on continuous evaluation of accessibility and quality of the cervical cancer screening program should also be developed.
- Implement a standardized routine facilitative supervision system in facilities that provide cervical cancer prevention services to ensure effective services.

Integrate quality assurance procedures into the process of licensing or accreditation of laboratories.

# Training and professional development

- Training and retraining of health providers are essential for the public as well as the private health sector (laboratory staff, GPs, nurses, gynecologists).
- Review the cervical cancer curricula in the medical and nursing schools and identify areas that require updating so that they reflect the current national norms and scientific knowledge of cervical cancer and its prevention and treatment.
- Develop a training strategy to strengthen the technical skills of laboratory personnel in all national laboratories.
- Develop a training strategy to strengthen health care personnel knowledge and counseling skills of patients.
- > Develop a strategy to conduct periodic assessments of the number of trained personnel that provide screening and treatment services to ensure performance to standards.
- Create a national school for cytology readers, promote the role of cyto-technicians, and adopt a national diagnostic classification in line with international standards. Increase the number of cytologists and cyto-technicians.

#### Infrastructure, equipment and supplies

> Determine mechanisms to ensure that secondary and tertiary level facilities have the equipment and supplies for providers to carry out diagnosis and treatment services.

#### Information and communication

- Implement at the state level, a population based computerized epidemiologic surveillance system for the cervical cancer screening program, with call and recall features.
- Improve the accuracy of the national cancer registry by link it to departments that have regional and local registries.
- Develop a standardized national information system to enable the evaluation of the cervical cancer prevention, diagnosis and treatment program.
- Develop communication strategies to facilitate coordination and feedback between cytology laboratories and health care facilities.

#### 4.2.2. Recommendations for health promotion

- Health professionals, health services managers and health policy makers should work together to orient the health system in favor of health promotion, as much as the treatment of ill-health.
- Primary health care should assume a central position in health promotion and disease prevention. General physicians, and other health care personnel such as nurses and midwives need to be involved in providing information about cervical cancer to women.
- > Target individual women with invitation letters and face to face communication to make informed decisions.

- Increase the level of awareness and information available to the community about cervical cancer prevention and treatment. Women should be enabled, through information and education, to acquire and maintain behavior that promotes their own reproductive health.
- Integrate health promotion messages into all public sector facilities and disseminate in communities.
- > Develop strategies to promote male involvement in cervical cancer prevention.

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