
FEMALE ONCOLOGIC DISEASES IN ROMANIA

Study conducted by **ISRA Center**, for
The Coalition for Women's Health and **Roche Romania**

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GLOSSARY

Incidence (percentage): number of new cancer cases occurring in a given period, in respect to a specified population. This report takes into account the annual incidence.

Prevalence (percentage): number of people within a population who have been diagnosed with that form of cancer and who are still alive at the end of a given period; this report presents the 5-year prevalence i.e. the number of people who have been diagnosed with cancer in the last 5 years and are still alive.

Mortality (percentage): number of deaths occurring in a given period as a result of that form of cancer, within a specified population. This report takes into account the annual mortality.

Annual survival rate: number of people diagnosed with cancer who are alive one year from receiving the diagnosis, in respect to the total number of people diagnosed that year. This is calculated dividing the annual mortality by the annual incidence and subtracting the ratio from 100%.

SUMMARY

This study represents a broad mobilization to “diagnose” the existing problems of the medical system in Romania in connection with three types of cancer affecting women: breast, cervical and ovarian.

The research includes both qualitative and quantitative methods, to create as complete and detailed a picture as possible and at the same time a detailed one for the issue in question. This study includes three categories of respondents: doctors involved in the screening process; healthy women, who could participate in screening programmes; and patients diagnosed with one of three types of cancer and their dependents, respectively. The perspective of the doctors was explored qualitatively, then confirmed quantitatively. The same research structure was also applied to healthy women, in order to mirror the two perspectives. The experiences of patients and dependents were explored qualitatively, through in-depth interviews.

Romania ranks second to last in Europe in terms of the percentage of the female population that has undergone a breast check-up at least once in their lifetime and last place when we consider the number of women who had the Babeş-Papanicolau

test done at least once in their lifetime. The effort to detect the three types of female cancers is even greater since studies reveal multiple problems that require a specific set of solutions.

On the one hand, there are problems related to insufficient funding of the health system. On the other hand, problems related to poor or ineffective communication of the prevention and early diagnosis programmes that already exist at national level are also highlighted. Added to this, the low level of education of the female population, in terms of preventive, as well as the complicated, long and inefficient path of patients in the medical system, the difficult access to high performance equipment and the increasingly acute lack of qualified medical personnel.

Furthermore, the list of compensated and free medicines is updated at an extremely slow pace, so many new treatments, already available in the European Union for these three types of cancers, cannot be accessed by patients in Romania.

Romania is among the last three European Union member states that has not yet implemented a national screening programme for breast cancer. This, despite breast cancer being the leading form of cancer affecting women. Perhaps it is also due to this fact that in Romania breast cancer is recording the lowest survival rate compared to the European average.

In conclusion, a financial optimization of the medical system needs to be achieved, with more resources allocated to prevention and early diagnosis programmes, by developing and implementing a screening programme for breast cancer, and appropriately promoting the existing screening programme for cervical cancer respectively.

It is absolutely imperative to increase the level of medical education of the population, in order to stimulate regular visits to the doctor and the performance of regular check-ups. This would allow a decrease in costs related to the management and treatment of breast cancer, given that a diagnosis of the disease in the early stages involves lower costs and increases both the chances of survival, and the recovery of patients for income-generating productive activity.

INTRODUCTION

The health system in Romania has many shortcomings, a fact widely known and long-discussed in the public arena. Beyond this finding, however, there is rather scarce data on the specific problems that patients, medical personnel, medical units, authorities and the general population are faced with, on each single therapeutic area. It is perhaps for this reason too, that the solutions proposed often encounter unforeseen obstacles, generate new problems that require other solutions or simply do not get to be implemented.

The situation of the main cancers affecting women - breast, cervical and ovarian cancer - illustrate very well the effects of solutions applied to problems which were not understood sufficiently well.

To make a real and significant contribution for the improvement in the way these three cancers are managed in Romania, the Coalition for Women's Health launched the most comprehensive study to "diagnose" the existing problems in the medical system and beyond.

In order to build an overall picture of the problem, it is necessary to assess the perspectives of all stakeholders. To this end, this study was structured around three categories of respondents: doctors involved in primary screening (gynecologists and GPs, radiologists and anatomopathologists respectively); women targeted by the screening, from the main age group (30-45 years); patients diagnosed with one of the three types of cancers and their dependents, respectively.

The study began by collecting statistical data available for Romania, to understand the background of the research. The next phase concentrated on GPs and gynecologists, whose perspective was explored first qualitatively, then confirmed quantitatively. The same research structure was also applied to healthy women, in order to mirror the two perspectives.

To confirm certain conclusions, radiologists and anatomopathologists, involved in more advanced screening phase, were interviewed. Finally, the experiences of patients and dependents were explored qualitatively, through in-depth interviews.

The study was conducted thanks to a grant offered by Roche Romania.

Chapter 1.
COMPARATIVE STATISTICS:
ROMANIA VERSUS EUROPEAN UNION

This research phase aimed to centralize publicly available statistical data for Romania, and the European average, respectively, in terms of incidence (annual), prevalence (5 years) and mortality (annual) of ovarian, cervical and breast cancers.

Note that, in the absence of a national register of patients diagnosed with cancer, the figures for Romania are estimated based on local registers such as the one from Cluj.

Table 1.1: Prevalence, incidence and mortality rates for breast, ovarian and cervical cancers in Romania, compared to the European Union average (2012)¹

	Prevalence (5 years)		Annual Incidence		Annual Mortality	
	RO	EU	RO	EU	RO	EU
Total number of people diagnosed	52,410	1,664,000	15,260	439,860	6,170	134,820
<i>Breast cancer</i>	33,390 (63.7%)	1,443,910 (86.8%)	8,980 (58.8%)	361,600 (82.2%)	3,240 (52.5%)	91,590 (67.9%)
<i>Cervical cancer</i>	14,830 (28.3%)	115,280 (6.9%)	4,430 (29%)	33,680 (7.7%)	1,910 (31%)	13,140 (9.7%)
<i>Ovarian cancer</i>	4,190 (8%)	104,810 (6.3%)	1,850 (12.2%)	44,580 (10.1%)	1,020 (16.5%)	30,090 (22.4%)
% of female cancers	55.8%	48%	42.6%	36.5%	31.9%	24%
<i>Breast cancer</i>	35.6%	41.2%	25.2%	30%	16.7%	16.3%
<i>Cervical cancer</i>	15.8%	3.3%	12.2%	2.8%	9.9%	2.3%
<i>Ovarian cancer</i>	4.4%	3%	5.2%	3.7%	5.3%	5.4%
% of female cancers	0.47%	0.64%	0.14%	0.17%	0.06%	0.05%
<i>Breast cancer</i>	0.3%	0.56%	0.08%	0.17%	0.03%	0.035%
<i>Cervical cancer</i>	0.13%	0.04%	0.04%	0.01%	0.02%	0.005%
<i>Ovarian cancer</i>	0.04%	0.04%	0.02%	0.02%	0.01%	0.01%

1 Mortalitatea Prin Cancer La Săn În România - 36%. Asociațiile De Pacienți Cer Program De Screening' (Mediafax.ro, 2015) <<http://www.mediafax.ro/stiinta-sanatate/mortalitatea-prin-cancer-la-san-in-romania-36-asociațiile-de-pacienți-cer-program-de-screening-14916174>> accessed June 30, 2016.

For breast cancer, incidence rate in Romania is almost 2 times lower within the total female population, which may indicate either that Romanian women are less exposed to the risk of developing this type of cancer (for example, because they are said to undergo fewer hormone replacement therapies), or that we are faced with under-diagnosis. Unfortunately, in the absence of centralized data with the history of patients, we can only speculate about the reasons for these differences.

On the other hand, mortality in Romania is not 2 times lower than the European average (as we would expect if mortality were correlated with the incidence in the same way), which supports the possibility of under-diagnosis - Romanian women are diagnosed later, when chances of survival are significantly lower.

The major difference is noted in the annual incidence of cervical cancer in Romania, compared to the European average: 12.2% of all female cancers versus 2.8%, more than four times higher. Most likely, this difference is due to the very low penetration of HPV vaccination in Romania, compared to other European countries.

The difference drops in the case of prevalence to 5 years - nearly three times higher in Romania - which is explained by the mortality rate, four times higher in Romania, compared to the European average. Thus, a large part of the patients are no longer alive 5 years after the diagnosis.

Regarding ovarian cancer, there is a notable difference only in terms of mortality (two times lower in Romania, compared to the European average), an aspect that is difficult to explain. We will be discussing in the next chapters about the low frequency of routine medical check-ups of Romanian women, so there is no reason to suppose that this disease is diagnosed earlier, when the chances of successful treatment are higher.

We will also be discussing about the fact that Romania is far behind other European countries in terms of access to new, innovative therapies, as well as in terms of waiting time for treatment. It is therefore likely that this difference may be due in fact to under-reporting, more so as there are no national registers of patients. Therefore, it is possible that some of the women who die from ovarian cancer in Romania are not reported as such.

Note that the overall mortality rate is higher in Romania, compared to the European average, while the total number of diagnosed cases (incidence) is visibly smaller in Romania, in relation to the population size.

Figure 1.1: Comparison between the cumulative rates of prevalence, incidence and mortality rates for breast, ovarian and cervical cancers, in relation to the total female population in Romania, and the European Union respectively (2012)

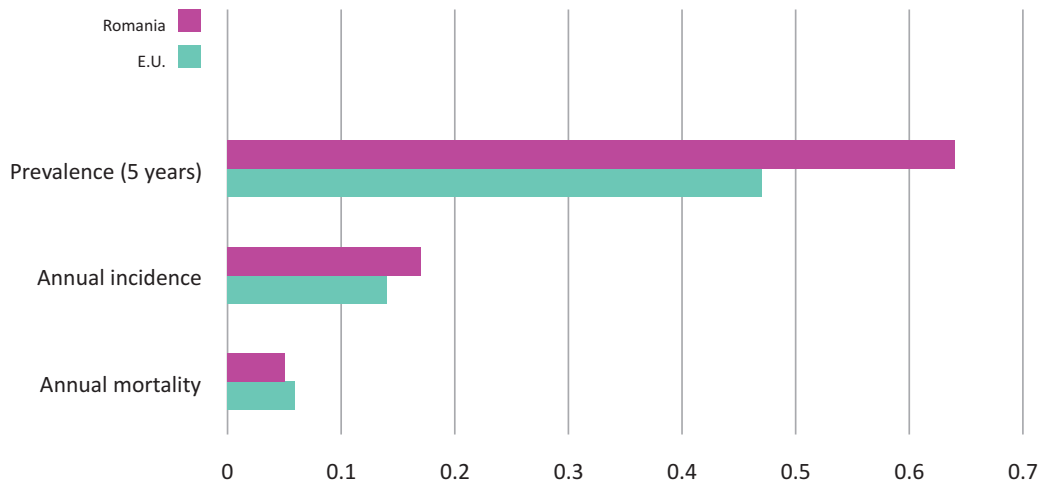
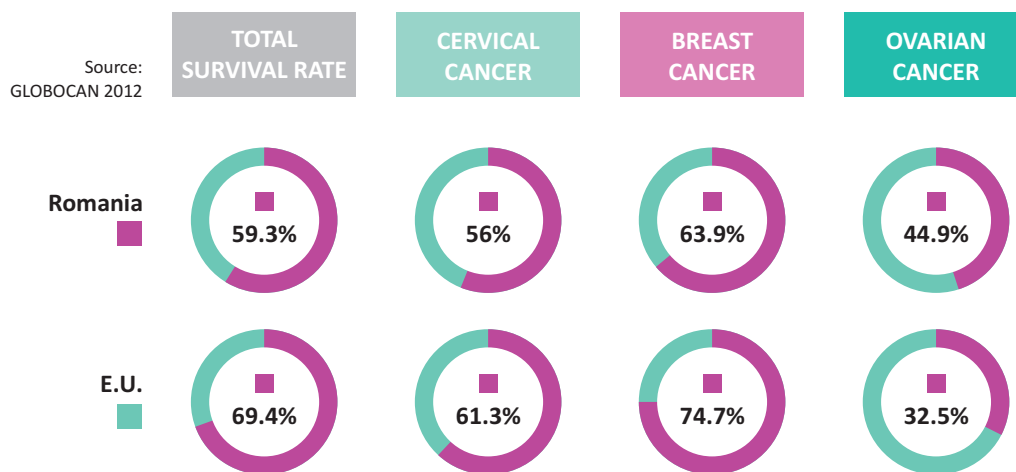


Figure 1.2: Survival rate of patients with breast, ovarian and cervical cancer in Romania, compared to the European Union average (2012)



The greatest difference between the survival rate in Romania and the European average appears in breast cancer - a consequence of the lack of screening programmes, low level of education (and even fear of investigations), difficult path of the patients through the medical system, as well as reduced access to new therapies - as we shall see in the following chapters.

Chapter 2.
PREVENTION AND SCREENING

Cancer prevention involves several stages. Primary prevention aims to reduce the incidence of cancer by eliminating the main risk factors, such as smoking, nutrition and poor physical activity. Secondary prevention aims to reduce cancer mortality, through early detection thereof, when chances of successful treatment are high. The best method for early detection is screening the entire population.

In 2003, the Council of the European Union unanimously adopted a set of Recommendations for cancer screening, inviting Member States to act in order to implement the principles of good practice described in the document, with the aim of developing screening programmes for breast, cervical and colorectal cancer, responsible for most cancer-related deaths worldwide. In order to help Member States to implement such programmes, the European Commission published guidelines for quality assurance in screening and diagnosis for breast, cervical and colorectal cancer².

2.1 Screening for Breast Cancer

The recommendations of the European Guidelines for quality assurance in breast cancer screening and diagnosis provide that annual mammographies should be done for women age 50-69 de years².

Currently, in Romania there is no national screening programme for breast cancer. The Ministry of Health announced in April 2016 that it will strive to remedy this problem with the launch of the Integrated Multi-Annual National Cancer Control Plan, for which it seeks to obtain financing through European funds dedicated to screening programmes for breast cancer. In the first phase, we will be dealing with a pilot programme, conducted in the national institutes of Iasi, Bucharest and Cluj³.

The only existing screening campaigns are initiated by patient organizations or other non-profit, non-governmental organizations. For example, “Federația Asociațiilor Bolnavilor de Cancer” (the Federation of Cancer Patients Associations) annually holds, in rural areas, the “*Nu am făcut destul*” (“*I haven’t done enough*”) campaign, which has reached in 2016 its 3rd edition. In the 2015 campaign 1,025 women from 7 counties were tested, for 83.7% of them this being the first medical examination of the breasts that they had ever made, 88.7% of them having done no self-examination of

2 (2003) <<http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2003:327:0034:0038:EN:PDF>> accessed August 17, 2016.

3 ‘Fonduri Europene Pentru Un Program De Preventie A Cancerului’ (Ziare.com, 2016) <<http://www.ziare.com/social/spital/fonduri-europene-pentru-un-program-de-preventie-a-cancerului-1416760>> accessed August 30, 2016.

the breasts in their life⁴. 8.5% of the participants presented breast cancer suspicions, more than a quarter of them being under 40 years of age. In the 2016 campaign, 1129 women were tested, the results being slightly better than in the previous year, in terms of regular testing: “only” 72% of women were undergoing breast check-up for the first time in their life, and “only” 49.9% never having done any self-examination of the breasts, respectively. Note that this testing campaign was not conducted in the same areas or towns as the one in 2015. But more participants presented breast cancer suspicions in 2016 - 19.7% - 17.1% of them being under 40 years of age⁵.

Similarly, Fundația “Renașterea” (“Renaissance” Foundation) is conducting as of 2007 a screening programme (“Diagnostic mobil” - “Mobile diagnosis”) for breast cancer and cervical cancer⁶. Until now, the Mobile Diagnosis Unit visited more than 40 localities from 21 counties, where over 16,800 low-income women have received free medical examinations (9.126 mammographies, 15.980 Babeș-Papanicolau tests). From the 2015 caravan only 59% of the women tested were declared healthy, 38.5% received a recommendation for further investigations, and 2.5% received direct recommendation for oncology consultation.

In 2015, the “Ion Chiricuță” Oncology Institute initiated in Cluj a pilot screening programme for breast cancer. Its goal is to see 5,000 women and to offer free mammographies to women from disadvantaged social backgrounds, while carrying out at the same time a feasibility study for a national screening programme for breast cancer. The project, supported by Norwegian funds, is an extension of the CEDICROM programme, designed for early detection of cervical cancer among disadvantaged populations in the North-West of the country^{7,8}. Until the 30th December 2016 all the 5.000 mammographies with dual reading with arbitration have been carried out, with the feasibility study for a national programme being still in progress⁹.

Romania is one of the only three countries in the European Union which has no national screening programme for breast cancer, despite the fact that it is the most common type of cancer affecting women.

4 Mortalitatea Prin Cancer La Sân În România - 36%. Asociațiile De Pacienți Cer Program De Screening' (Mediafax.ro, 2015) <<http://www.mediafax.ro/stiinta-sanatate/mortalitatea-prin-cancer-la-san-in-romania-36-asociatiile-de-pacienti-cer-program-de-screening-14916174>> accessed June 30, 2016.

5 Raportul Federației Asociațiilor Bolnavilor de Cancer, 2016, „Nu am făcut destul” campaign (2008 – present) in the rural environment, accessed June 30, 2016.

6 ‘Unitatea Mobila | Fundatia Renasterea’ (Fundatiarenasterea.ro, 2016) <<http://fundatiarenasterea.ro/unitatea-mobila/>> accessed September 4, 2016.

7 ‘Peste 5.000 De Clujence Vor Putea Sa-Si Faca Mamografiile Gratuite In Cadrul Unui Program Finantat De Norvegieni’ (Ziar de Cluj, 2015) <<http://www.ziardecluj.ro/peste-5000-de-clujence-vor-putea-sa-si-faca-mamografiile-gratuite-cadrul-unui-program-finantat-de-norvegieni>> accessed September 11, 2016.

8 ‘Screening Gratuit Pentru Depistarea Cancerului La San, La Cluj’ (Edumedical.ro, 2015) <<http://www.edumedical.ro/screening-gratuit/>> accessed September 16, 2016.

9 Results’ (Cedicrom.ioen.ro, 2016) <<http://cedicrom.ioen.ro/html/rezultate.html>> accessed September 17, 2016.

Table 2.1: Screening programmes for breast cancer available in the European Union countries¹⁰

Region/ State	Type of programme and coverage		Screening method	Screening interval (years)	Age interval	Starting date	National coverage achieved in
Austria	NR	National	MA	2	>40	1974	-
	NP	Regional	MD	1/2	40–59/ 60–69	2007	2008
Belgium	NP	National	MD	2	50–69	2001	-
Bulgaria	NR	Local	MA	-	45–69	2011	-
Czech Rep.	NR	National	MA MD	2	45–69	2002	2007
Cyprus	NP	National	MD	2	50–69	2003	2006
Croatia	NP	National	MA MD	2	50–69	-	2006
Denmark	NP	National	MD	2	50–69	1991	2010
Estonia	NP	National	MD	2	50–65	2002	2007
Finland	NP	National	MD	2	50–69	1987	1989
France	NP	National	MA MD EC	2	50/74	1989	2004
Germany	NP	National	MA MD	2	50–69	2005	2009
Greece	NR	Pilot	MA	1/2	40–50/64	-	-
Ireland	NP	National	MD	2	50–64	2000	2008
Italy	NP	National	MA MD	2	50–69 (74)	1990	2007
Latvia	NP	National	MA MD	2	50–69	2008	2009
Lithuania	NP	National	MA	2	50–69	2005	-
Luxembourg	NP	National	MD	2	50–69	1992	1992
Malta	NP	National	MD	3	50–59	2008	2009
Netherlands	NP	National	MD	2	50–74	1988	1997
Poland	NP	National	MD	2	50–69	2006	2007
Portugal	NP	National	MD	2	45–69	1990	2005
United Kingdom	NP	National	MA MD	3	50–(64) 70	1988	1995
Romania	NR	Local	MA	(3) (2) 1	40+	-	-
Slovakia	NR	-	-	2	40+	-	-
Slovenia	NP	National	MD	2	50–69	2008	-
Spain	NP	National	MA MD	2	(45) 50–69	1990	2009
Sweden	NP	National	MA MD	(1,5) 2	40 (50)– (69) 74	1986	1996
Hungary	NP	National	MA	2	45–65	2002	-

Legend:

NP = the level of the entire population; NR = limited level (without population-wide coverage); MD = digital mammography; MA = analogical mammography; EC = clinical examination

10 E. Altobelli and A. Lattanzi, 'Breast Cancer In European Union: An Update Of Screening Programmes As Of March 2014 (Review)' (2014) <<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4203333/>> accessed September 4, 2016.

Romania ranks last in the European top in terms of the percentage of the female population who had one breast examination (mammography) done at least once in life - far behind Greece and Slovakia, the other two countries that have no national screening programme for breast cancer.

Figure 2.1: Breast cancer screening (mammography) at least once in life: women in the age range of 50-69 years¹¹

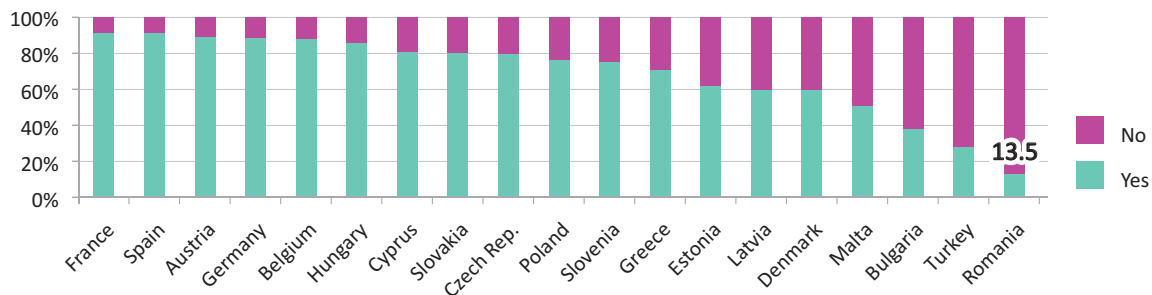
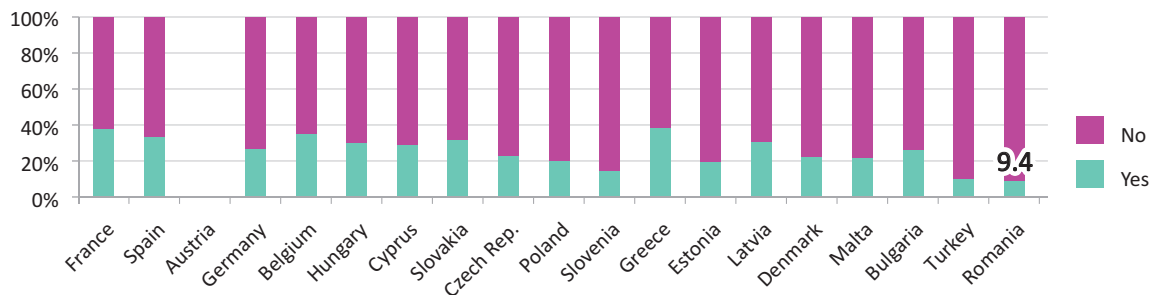


Figure 2.2: Breast cancer screening (mammography) at least once in life: women under the age of 50¹²

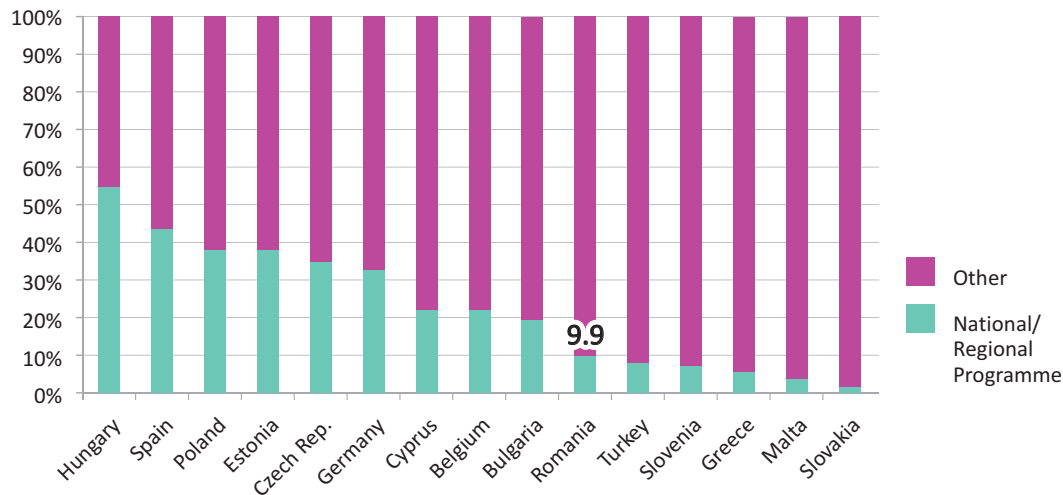


Although the absence of a national screening programme largely explains the very low presence of Romanian women at the screening check-ups, this cannot be the only reason, evidence being the fact that the two other European countries that also have no national screening programme, have a much higher rate of visits to the doctor. When asked about the reason why they came for screening-type check-ups for breast cancer, many women invoked “other reasons”.

¹¹ 'European Health Interview Survey - Eurostat' (Ec.europa.eu, 2010) <<http://ec.europa.eu/eurostat/web/microdata/european-health-interview-survey>> accessed August 27, 2016.

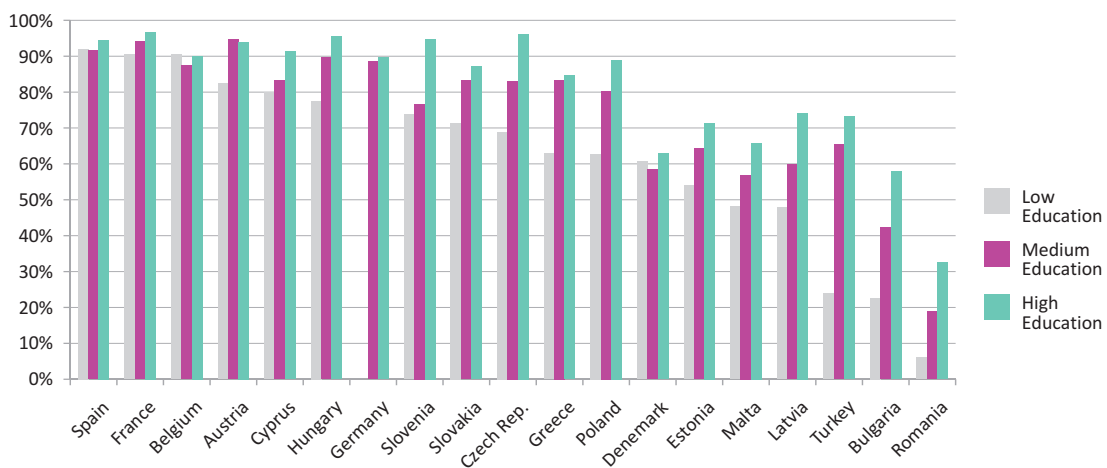
¹² *Ibidem*

Figure 2.3: Reason for a screening investigation for breast cancer: women over 15 years old¹³



The reasons for failure to visit the doctor for regular check-ups are difficult to define. Formal education level seems to play a greater role in Romania, compared to other countries. This could be explained by the lack of health education curricula in primary school, secondary school and high school or by the lack of health education programs addressed to the general public. Thus, there are greater differences between the level of knowledge about health of women with higher education, compared to those who have completed their formal education earlier. In any case, it is worth noting that women with higher education do not go for screening check-ups for breast cancer, Romania ranking in last place in the European top under all education categories.

Figure 2.4: Breast cancer screening depending on the level of education: women in the age range of 50-69 years¹⁴



13 'European Health Interview Survey - Eurostat' (Ec.europa.eu, 2010) <<http://ec.europa.eu/eurostat/web/microdata/european-health-interview-survey>> accessed August 27, 2016.

14 *Ibidem*

Other possible reasons could be related to the costs of investigations (which are not always available free of charge in sufficient numbers, due to reimbursement thresholds that are too low), to the difficult access to specialized practitioners or equipment or simply due to cultural aspects that fail to fore prevention and regular contact with the doctor.

2.2 Screening for Cervical Cancer; HPV Vaccination

Unlike breast cancer, for cervical cancer there are both regional initiatives (such as CEDICROM, whereby 10,000 Babeş-Papanicolau tests were carried out by 30th of December 2016¹⁵), and a national screening programme launched in August 2012, over a period of 5 years.

This programme is dedicated to women between 25 and 64 years of age, regardless of their insurance status, as long as they have no diagnosis of cervical cancer or a history suggestive of this pathology confirmed¹⁶.

The Ministry of Health has proposed, for 2012, to test over 200,000 eligible women (100 RON being allocated for each testing process), and for the entire duration of the testing program, 6 million women⁹. By the end of 2015, the number of women tested had reached 630,000, the coverage rate being 10.5% of the target population¹⁷.

The programme encountered numerous difficulties. The lack of an electronic data base makes it impossible to centralize the information obtained and generate statistics in order to track the progress of the screening campaign and solve the problems arisen along the way. In Timișoara, the coordinators have organized themselves and created an electronic program for that purpose¹⁸. The results of this effort, however, were not published.

The lack of a clear legal basis for the employment and remuneration of the health professionals involved in the programme (for state centers) raises problems for

15 Results' (Cedicrom.iocn.ro, 2016) <<http://cedicrom.iocn.ro/html/rezultate.html>> accessed September 17, 2016.

16 'Programul National De Screening Pentru Cancerul De Col Uterin' (Iocn.ro) <<http://www.iocn.ro/Centrul-de-prevenire-si-control-al-cancerului/Programul-de-screening-pentru-cancerul-de-col-uterin/Informatii-de-interes-general.html>> accessed August 20, 2016.

17 'Dr. Carmen Ungurean: Aproximativ 630.000 De Femei, Testate De La Demararea Programului De Screening Pentru Cancerul De Col – AGERPRES' (Agerpres.ro, 2016) <<http://www.agerpres.ro/sanatare/2016/03/31/dr-carmen-ungurean-aproximativ-630-000-de-femei-testate-de-la-demararea-programului-de-screening-pentru-cancerul-de-col-14-08-22>> accessed August 25, 2016.

18 'Cum Îngroapă Ministerul Sănătății O Campanie De 140 Milioane De Euro Împotriva Cancerului | Romania Libera' (RomaniaLibera.ro, 2013) <<http://www.romanalibera.ro/special/investigatii/cum-ingroapa-ministerul-sanatatii-o-campanie-de-140-milioane-de-euro-impotriva-cancerului-295110>> accessed August 20, 2016.

the physicians enrolled in the screening programme. Health professionals must first become authorized freelancers to be able to enroll in the programme. The GP should receive 15 lei for each woman he/she informs about the programme. 28 lei are due to the healthcare professional collecting the blade for the test, 37 lei are due to the laboratory where the analysis is made¹⁹. The time required for these procedures is however included in the normal workday of such health professionals, which means the screening procedure is in “competition” with other procedures, with varying degrees of urgency or severity and possibly with potential for higher remuneration.

Not all GPs^{20, 21, 22} are registered in the programme, which means a great number of women do not find out about it or cannot access it - the collection of the test specimen done either in the practice of the GP, or at a collection center, after filling out a form also received from the GP. GPs²³ blame the lack of clear procedures for the implementation of the programme, the lack of its promotion among the general public and healthcare professionals overuse - issues that this study shall be detailing in Chapter 4.

Enhancing the performance of the screening programme for cervical cancer is on the agenda of the Integrated Multi-Annual National Cancer Control Plan, which also aims to introduce a regional pilot primary screening programme for HPV, according to recent recommendations of the European Guidelines²⁴.

19 ‘In Nicio Tara Din UE Nu Se Moare De Cancer Ca In Romania. Pana Si Singurul Program De Preventie Este Sabotat De Unii Medici’ (stirileprotv.ro, 2015) <<http://stirileprotv.ro/stiri/sanatate/romania-lider-in-ue-la-mortile-cauzate-de-cancer-cum-ajung-doctorii-de-familie-sa-saboteze-programele-de-preventie.html>> accessed August 8, 2016.

20 *Ibidem*

21 ‘Ungurean (INSP): 471.000 De Femei Au Fost Testate De La Începerea Programului De Screening Pentru Cancerul De Col Uterin – AGERPRES’ (Agerpres.ro, 2015) <<http://www.agerpres.ro/sanatate/2015/03/03/ungurean-insp-471-000-de-femei-au-fost-testate-de-la-inceperea-programului-de-screening-pentru-cancerul-de-col-uterin-13-49-56>> accessed August 19, 2017.

22 ‘Odată Perfecționat, Programul Național De Screening Pentru Cancerul De Col Uterin Va Da Roade’ (Politici de Sanatate, 2015) <<http://www.politicidesanatate.ro/odata-perfectionat-programul-national-de-screening-pentru-cancerul-de-col-uterin-va-da-roade/>> accessed July 10, 2016.

23 ‘In Nicio Tara Din UE Nu Se Moare De Cancer Ca In Romania. Pana Si Singurul Program De Preventie Este Sabotat De Unii Medici’ (stirileprotv.ro, 2015) <<http://stirileprotv.ro/stiri/sanatate/romania-lider-in-ue-la-mortile-cauzate-de-cancer-cum-ajung-doctorii-de-familie-sa-saboteze-programele-de-preventie.html>> accessed August 8, 2016.

24 (2016) <<http://www.sanatateabuzoiana.ro/primul-plan-national-multianual-integrat-de-control-al-cancerului-in-romania/>> accessed August 5, 2016.

Table 2.2: Screening programmes for cervical cancer available in the European Union countries^{25*}

Region/ State	Screening type	Screening status	Starting year	Test type	Targeted age interval	Testing frequency (years)	Coverage
Austria	Opportunistic	National	N/A	CC	18+	1	N/A
Belgium	Opportunistic	National	N/A	CC	25–64	3	70%
Bulgaria	Opportunistic	National	~ 1995	CC	30–59	3	N/A
Czech Rep.	Organized	National	2008	CC	25–60	1	48%
Cyprus	-	-	-	-	-	-	-
Croatia	Opportunistic	National	1953	CC + CML	25–64	3	35%–42%
Denmark	Opportunistic	National	?	CC	23–65	3 for 23–50 years / 5 for 50+	69%
Estonia	Opportunistic	National	2006	CC	30–59	3	12.70%
Finland	Organized	National	1963	CC	(25) 30–60 (65)	5	73%
France	Opportunistic + Organized in 5 regions	National	N/A	CC	20 (25) +	3	71%
Germany	Opportunistic	National	N/A	CC	20+	1	N/A
Greece	Opportunistic	National	N/A	CC	20+	1	N/A
Ireland	Organized	Regional; National in plan	2008	CML	25–65	3 for 25–44 years / 5 for 45+	62%–66%
Italy	Organized	National	2004	CC	25–64	3	>59%
Latvia	Organized	National	2009	CC	25–70	3	42%
Lithuania	Organized	National	2004	CC	25–60	3	9%–17% (39%)
Luxembourg	Opportunistic	National	N/A	CC	15+	1	N/A
Malta	-	-	-	-	-	-	-
Netherlands	Organized	National	N/A	CC	30–60	5	77%
Poland	Organized	National	2006	CC + CML	25–59	3	22.6%–26.8%
Portugal	Organized in 3 regions	National	N/A	CC	25–64	3	58%
UK	Organized	National	1988	CML	(20) 25–60 (64)	3	74%
Romania	Opportunistic+ Regional pilot	National	1965 Pilot 2002–2006	CC + CML	25–64	3	18.4% (10% regional)
Slovakia	Opportunistic	National	1980	CC	23–64	3	17%–20%
Slovenia	Organized	National	2003	CC	20–64	3	70%–74%
Spain	Opportunistic + Organized reg.	Regional	N/A	CC	30–65	3	N/A
Sweden	Organized	National	N/A	CC	23–60	3	73%
Hungary	Organized	National	2002	CC	25–65	3	28–31%

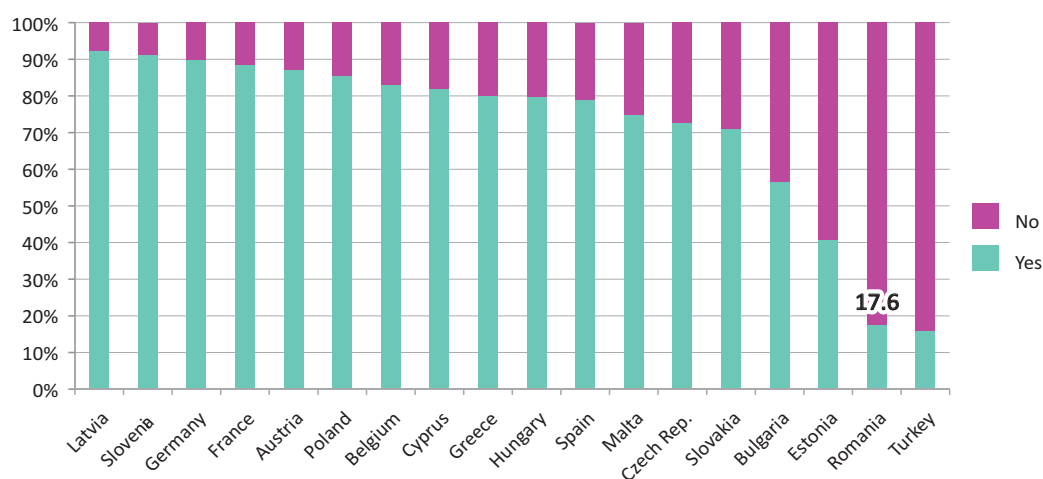
CC = Conventional Cytology CML = Liquid-Based Cytology

25 V. Kesic, M. Poljak and S. Rogovskaya, 'Cervical Cancer Burden And Prevention Activities In Europe' (2012) <<http://cebp.aacrjournals.org/content/21/9/1423.full>> accessed August 4, 2016.

* At the time of publication of the data in the source article (2012), the national programme was not yet established in Romania.

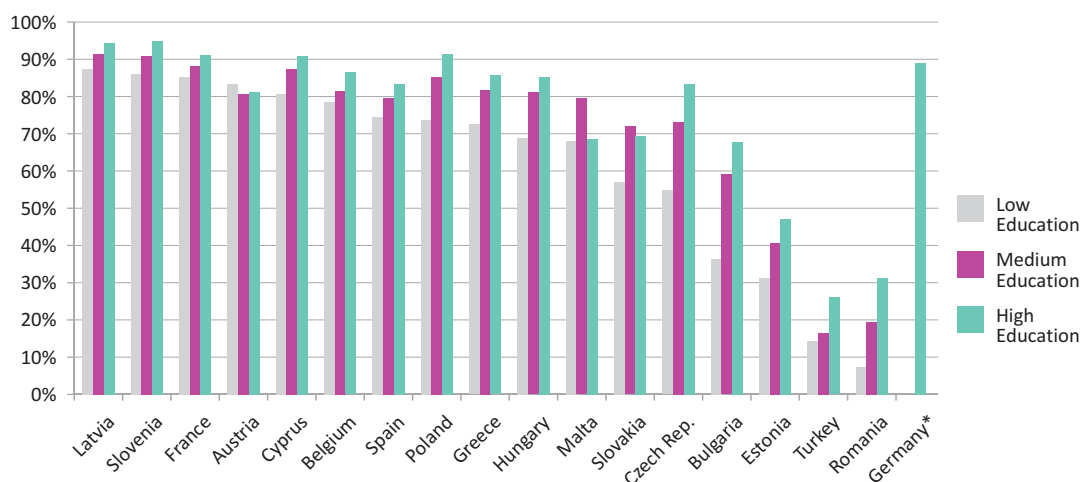
Romania ranks second to last in the European top regarding the percentage of the female population who did a Babeş-Papanicolau test at least once in life - again, very far behind the countries that have no national screening programme for cervical cancer (Cyprus and Malta) or Spain and Ireland, which at the time of publication of this data (2012) only had regional programmes.

Figure 2.5: Cervical cancer screening (Babeş-Papanicolau test) at least once in life: women in the age range 20-69 years²⁶



As with screening for breast cancer, the level of education seems to play an important role in Romania, in the sense that the differences between the frequency of participation of women with low, average and high education are higher than in other countries - possibly due to similar reasons to those listed for breast cancer screening.

Figure 2.6: Cervical cancer screening (Babeş-Papanicolau test) depending on the level of education: women in the age range of 20-69 years^{27*}



²⁶ 'Eurostat' (Ec.europa.eu, 2012) <<http://ec.europa.eu/eurostat>> accessed August 4, 2016.

²⁷ *Ibidem*

*For Germany only the data for the average level of education are available.

Regarding the prevention of cervical cancer through HPV vaccination and screening, in Romania two HPV vaccination campaigns were held so far, and the genotype test for determining the current HPV strains is not reimbursed by the National Health Insurance Fund (“Casa de Sanatate”).

The two vaccination campaigns generated modest results. The program was launched in November 2008, and in its first stage only 2,615 pupils in grade IV were vaccinated with the first dose, representing 2.57% of the eligible population at that time (girls who were then 10-11 years old). Among the reasons invoked for this failure were poor information of the parents and doctors, as well as the introduction of the concept of “informed refusal”. The Romanian State had bought at the time 303,000 doses of vaccine, worth 23 million euro²⁸. The programme was resumed in 2009, with a success rate only slightly higher. Vaccination continued until 2011, with the doses purchased in 2008-2009²⁹. Until the beginning of 2016, 150,000 girls had been immunized in total. Currently, with the absence of an active vaccination campaign, parents are forced to buy the vaccine³⁰. These immunizations carried out in private are not reported.

In 2013, “Asociația Națională pentru Protecția Pacienților” (National Association for Patient Protection) requested the Ministry to implement together with the organizations representatives of the civil society, a HPV vaccination programme on request.

2.3 Screening for Ovarian Cancer

For ovarian cancer, there are currently no screening procedures agreed by the international medical community, however, regular gynecological and endocrinological check-ups are recommended to maximize the chances of early detection of this type of cancer.

In Romania, information campaigns regarding this type of cancer have a limited nature, being generally initiated by patient organizations. For example, the “#AcumȘtiu” (*Now I Know*) campaign is organized by the “Federația Asociațiilor Bolnavilor de Cancer” on the occasion of the International Day against Ovarian Cancer (May 8th)³¹.

28 ‘Vaccinarea Împotriva Cancerului De Col Uterin, Un Eșec’ (Mediafax.ro, 2009) <<http://www.mediafax.ro/social/vaccinarea-impotriva-cancerului-de-col-uterin-un-esec-3766878>> accessed August 11, 2016.

29 ‘SOLICITARE CATRE MINISTERUL SANATATII - Acces La Datele Medicale Din Foaia De Observatii Din Spital | Programe Proprii’ (Protectiapacientilor.ro, 2013) <<http://www.protectiapacientilor.ro/>> accessed August 11, 2016.

30 ‘O Nouă Tentativă: Medicii Cer Reluarea Campaniei De Vaccinare A Fetițelor Împotriva HPV’ (REALITATEA.NET, 2016) <https://www.realitatea.net/o-noua-tentativa-medicii-cer-reluarea-campaniei-de-vaccinare-a-fetitelor-impotriva-hpv_1874585.html> accessed August 12, 2016.

31 ‘Campanie - Cancer Ovarian 2016’ (Federatia Asociatiilor Bolnavilor de Cancer din Romania, 2016) <<http://fabc.ro/campanie-cancer-ovarian-2016/>> accessed August 4, 2016.

The campaign encourages women to go to the gynecologist, to increase the chances of early detection of ovarian cancer. Also, women are provided with a questionnaire whereby they may find out if they present a high risk of developing this form of cancer.

There are also private clinics which provide the possibility to carry out some genetic tests, intended to detect the presence of BRCA1 and BRCA2 gene mutations, associated with an increased risk of developing breast or ovarian cancer, respectively^{32, 33}. But these types of tests are not reimbursed by the “National Health Insurance Fund” and their cost exceeds the average possibilities of women in Romania.

Ovarian cancer is not on the list of priorities of the National Health Strategy for 2014-2020, and so far there have been no information or education campaigns implemented nationally.

³² Women’s blog, ‘Teste Pentru Cancerul Mamar Și Ovarian’ (Donna Medical Center) <<http://www.donna-medicalcenter.ro/blog/teste-genetice-pentru-cancerul-mamar-si-ovarian.html>> accessed September 12, 2016.

³³ ‘Cancerul ereditar de san si ovarian’ (synevo) <<https://www.synevo.ro/mutatii-brca1-cancer-ereditar-sanovar>> accessed September 12, 2016.

Chapter 3.
**MANAGEMENT OF FEMALE CANCERS
IN ROMANIA**

3.1 Treatment Facilities

3.1.1 Hospitals and Clinics with Expertise in Oncology

The health service reform is a continuous process that produces changes in the health system infrastructure. The network of health units recorded, in 2014, important changes, the most significant being represented by the increasing number of hospitals as well as other types of healthcare facilities, the only decrease being recorded in the independent general medicine practices.

The promoter of these changes is the private sector, which is undergoing a continuous process of development.

Table 3.1: Functional health units in Romania (2013-2014)³⁴

	2013	2014	Public 2014	Private 2014	2014 vs. 2013 (+/-)	2014 vs. 2013 Public (+/-)	2014 vs. 2013 Private (+/-)
Hospitals	499	527	366	161	28	1	27
Outpatient facilities integrated within hospitals	341	351	322	29	10	3	7
Specialist outpatient facilities	92	97	49	48	5	-4	9
Independent family medicine practices	11,158	11,163	5,475	5,688	5	-34	39
Independent general medicine practices	966	795	20	775	-171	-1	-170
Independent specialist medical practices	10,160	10,063	954	9,109	-97	16	-113
Polyclinics	298	297	10	287	-1	-1	---
Specialist medical centers	249	309	36	273	60	1	59
Diagnosis and treatment centers	35	37	7	30	2	---	2
Medical laboratories	3,290	3,418	1,960	1,458	128	32	96

34 National Statistics Institute | Institutul National De Statistica' (Insse.ro, 2015) <<http://www.insse.ro/cms/>> accessed August 26, 2016.

The changes in the structure and number of health units have led to changes in the number of beds available in hospitals and other medical units.

In the public sector, the number of beds has seen a significant decline in 2014, while the setting up of new health units in the private sector led to an increase in the number of beds.

Table 3.2: Number of beds available in the hospitals in Romania (2013-2014)³⁵

	2013	2014	Public 2014	Private 2014	2014 vs. 2013 (+/-)	2014 vs. 2013 Public (+/-)	2014 vs 2013 Private (+/-)
TOTAL beds in hospitals	130,708	130,963	125,192	5,771	255	-435	690
Psychiatry	16,540	16,503	16,341	162	-37	-18	-19
Surgery	14,105	14,000	13,168	832	-105	-119	14
Internal	12,496	12,146	11,791	355	-350	-340	-10
Obstetrics-Gynecology	9,076	8,904	8,281	623	-172	-171	-1
Pneumology	9,059	8,899	8,899	---	-160	-140	-20
Physical Recovery/Balneology	6,962	7,267	6,584	683	305	66	239
Cardiology	5,621	5,725	5,434	291	104	47	57
Neurology	5,450	5,457	5,414	43	7	-5	12
Infectious Diseases	5,422	5,378	5,378	---	-44	-44	---
Oncology	4,155	4,183	3,891	292	28	-24	52
ATI (Anaesthesia and ICU)	4,899	4,966	4,611	355	67	53	14

35 National Statistics Institute | Institutul National De Statistica' (Insse.ro, 2015) <<http://www.insse.ro/cms/>> accessed August 26, 2016.

Table 3.3: Number and type of medical units with expertise in oncology in Romania, per locality³⁶

Town	Total clinics/practices	Number of clinics/practices offering the following services:							
		Oncology	Oncological surgery	Radiotherapy	Chemotherapy	Hematology/Stem cell transplant	Anatomopat. Laboratory	Tumor imaging diagnosis	Interventional Radiology
Alba Iulia	1	1							
Alexandria	1	1	1	1					
Arad	4	4						1	1
Bacau	2	2						1	
Baia Mare	3	3						1	
Brasov	4	3	2	1		1	1		
Bucharest	31	30	8	6	6		1	8	5
Calarasi	1	1							
Cluj	9	9	1	1	1				
Constanta	5	5		1			1	1	1
Craiova	6	6	1	1	1				
Dej	2	2							
Drobeta Tr. Severin	1	1				1	1		
Focsani	3	2	2	1	1		1	1	
Galati	2	2			1			1	
Iasi	3	3					1		
Medias	1	1							
Oltenita	1	1							
Oradea	5	2	1				1	2	1
Otopeni	1	1		1	1			1	
Pitesti	2	2	1	1	1				
Ploiesti	2	2	1	1	1			1	
Ramnicu Vâlcea	3	3			1		1		
Sibiu	3	3							
Suceava	1							1	1
Targoviste	2	2							
Targu Jiu	1	1							
Targu Mures	3	2						1	1
Timisoara	3	2	1			1	1	1	1
Turda	2	2							
Turnu-Magurele	1	1							
TOTAL	109	103	19	15	14	3	9	21	11

36 'Lista Cu Spitale Si Centre De Oncologie' (Ghid-cancer.ro, 2016) <<http://www.ghid-cancer.ro/spitale-oncologie>> accessed July 7, 2016.

3.1.2 Medical Equipment for Investigation and Treatment

The fitting of health units with specific medical devices has not undergone major changes, according to the latest official data published by the official National Statistics Institute. While the number of computerized tomography devices increased in 2014 compared to 2013 (especially in the private sector), the number of radiation therapy equipment decreased during the same period.

Table 3.4: Number and type of medical devices available in Romania (2013-2014)³⁷

Type of device	2013	2014	Public 2014	Private 2014	2014 vs. 2013 (+/-)	2014 vs. 2013 Public (+/-)	2014 vs. 2013 Private (+/-)
Computed Tomography (CT)	194	214	121	93	20	5	15
Positron Emission Tomography (PET)	5	5	1	4	---	---	---
Gamma Devices	45	44	35	9	-1	---	-1
Magnetic Resonance Imaging (MRI)	87	94	36	58	7	1	6
Radiation Therapy (RAD)	78	71	62	9	-7	-6	-1
Mammography	136	150	96	54	14	5	9

3.1.3 Medical Personnel Available

In 2014 the health system was serviced by 291,887 health professionals. Of these, 35% (102,268 persons) represent health professionals with high qualification (doctors, dentists, pharmacists, physiotherapists and auxiliary specialists: dental technicians, biologists, chemists, etc.), 44.2% (128,899 persons) represent health professionals with average training (nurses) and 20.8% (60,720 persons) represent auxiliary health staff. In 2014 the number of physicians was 54,929 people, 1.6% more than in 2013. However, the number of medical and sanitary professionals active in Romania in relation to 100,000 inhabitants is still lower compared to most European countries.

³⁷ National Statistics Institute | Institutul National De Statistica' (Insse.ro, 2015) <<http://www.insse.ro/cms/>> accessed August 26, 2016.

Table 3.5: Number of medical and sanitary professionals that serve 100,000 inhabitants in the European Union (2013)³⁸

Country	Year 2013	Country	Year 2013
Albania	:	Latvia	319
Austria	499	Liechtenstein	324
Belgium	295	Lithuania	428
Bulgaria	398	Luxembourg	281
Croatia	303	Malta	346
Cyprus	320	Muntenegro	215
Czech Republic	369	The Netherlands	:
Denmark	365	Norway	431
Estonia	328	Poland	224
Finland	302	Portugal	:
Former Yugoslav Republic of Macedonia	:	Romania	264
France	310	Serbia	:
Germany	400	Slovakia	:
Greece	:	Slovenia	263
Hungary	321	Spain	381
Iceland	361	Sweden	412
Ireland	269	Switzerland	404
Italy	390	Turkey	:
	---	United Kingdom of Great Britain	277

Table 3.6: Number of specialist physicians involved in the primary management of gynecological and breast cancers in Romania³⁹

	2013	2014	Public 2014	Private 2014	2014 vs. 2013 (+/-)	2014 vs. 2013 Public (+/-)	2014 vs. 2013 Private (+/-)
TOTAL physicians	54,086	54,929	40,658	14,271	843	600	243
Obstetrics-Gynecology	2,347 (4,3%)	2,417 (4,4%)	1,724	693	70	56	14
Oncology	523 (1%)	577 (1%)	483	94	54	43	11

38 'Eurostat - Tables, Graphs And Maps Interface (TGM) Table' (Ec.europa.eu, 2016) <<http://ec.europa.eu/eurostat/tgm/table.do?tab=table&init=1&language=en&pcode=tps00044&plugin=1>> accessed August 24, 2016.

39 National Statistics Institute | Institutul National De Statistica' (Insse.ro, 2015) <<http://www.insse.ro/cms/>> accessed August 26, 2016.

3.2 Treatment Options and Access to it

Access to treatment represents one of the most important stages of the path of patients diagnosed with cancer. In Romania, thousands of patients have to wait for two to six months to receive drug treatment. Moreover, the list of free and compensated medicines is updated at very wide intervals of time, which means that access to new, innovative treatments is significantly delayed.

There is currently a considerable discrepancy between the treatments available to patients in other European countries and those accessible to Romanian patients, which represents a limitation of the rights of Romanian patients to state-of-the-art treatments. In the period 2008 - 2015, the European Medicines Agency (EMA) approved 62 new original drugs against cancer. Only 7 are currently found on the list of compensated drugs in Romania⁴⁰.

An European study shows that, between the time of approval of a drug by EMA and the moment it can be prescribed with compensation by doctors in Belgium one has to wait 392 days, in Sweden 206 days, while in Austria only 88 days. In Romania one waits over 1,800 days⁴¹.

Cancer treatment has evolved greatly in recent years, for most types of cancer, including ovarian cancer. Nevertheless, female patients in Romania can have quicker access to the newest therapies only when their financial status allows the purchase.

On the other hand, since May 2014, the National Oncology Programme provides access to breast reconstruction surgeries by endoprosthesis for patients who underwent mastectomy surgery following diagnosis with breast cancer. The access to the programme is however modest: of the 800 operations for which funds have been secured in 2015, only 200 were performed, the reasons invoked being the lack of information (most women do not know about the existence of this possibility), and also fear of another surgical intervention⁴². The same programme also provides the re-introduction under compensation of the PET-CT investigation (high resonance scanning for the detection and staging of cancer)⁴³.

40 'Eurostat - Tables, Graphs And Maps Interface (TGM) Table' (Ec.europa.eu, 2016) <<http://ec.europa.eu/eurostat/tgm/table.do?tab=table&init=1&language=en&pcode=tps00044&plugin=1>> accessed August 24, 2016.

41 'Bolnavii De Cancer Din România, Tratați Cu Medicamente Vechi | Romania Libera' (RomaniaLibera.ro, 2013) <<http://www.romanalibera.ro/societate/utile/bolnavii-de-cancer-din-romania--tratati-cu-medicamente-vechi-292396>> accessed July 15, 2016.

42 'Reconstrucția Mamară, Dreptul La O Viață Normală' (Digi24.ro, 2015) <<http://www.digi24.ro/magazin/stil-de-viata/viata-sanatoasa/reconstrucția-mamara-dreptul-la-o-viata-normală-467136>> accessed August 22, 2016.

43 'MS: Pacientele Cu Cancer Mamar Vor Avea Acces La Tratamente De Ultima Generatie Si Operatii De Reconstructie Mamara' (Sanatateatv.ro, 2014) <<http://www.sanatateatv.ro/stiri-medicale/ms-pacientele-cu-cancer-mamar-vor-avea-acces-la-tratamente-de-ultima-generatie-si-operatii-de-reconstructie-mamara/>> accessed August 6, 2016.

Chapter 4.
**THE PERSPECTIVE OF THE PHYSICIANS
INVOLVED IN THE SCREENING PROCESS
OF FEMALE CANCERS**

4.1 Premises and Research Methodology

As indicated by the statistics quoted above, the screening process proves to be essential in the early detection and successful treatment of cancer. The screening process involves several stages, from the attention paid to one's own body and symptoms more or less obvious, the visit to the doctor for routine check-ups, moving then through various stages of investigations and specialist consultations, until obtaining a confirmed diagnosis.

The first steps on this path - self-examination and regular visits to the doctor, respectively, even in the absence of a symptomatology perceptible to the patient - are key moments in starting an effective health management process, based on early diagnosis of any medical problem, when the chances of successful treatment are maximum. Unfortunately, these steps seem to be systematically ignored in Romania, which explains, in part, the lower rates of survival of patients with gynecological and breast cancers.

We therefore intend to investigate the reasons why screening is not done in Romania, apparently regardless of the existence of a formal screening programme, at national level. We shall begin by studying the level of knowledge, but also the perceptions and attitudes of the doctors who are on the "front line" of the screening process - gynecologists and GPs - following both qualitative and quantitative methodologies. We shall verify certain conclusions from their answers with the help of other doctors involved in more advanced screening stages - anatomopathologists and radiologists. We shall then continue the investigation among women, to get a complete picture.

The main objective of the study, aiming at GPs and gynecologist doctors, is understanding their attitudes regarding the screening programmes, namely the barriers and challenges they are facing in implementing them. The questions asked concern:

- Attitude of doctors towards temporary campaigns and national screening programmes, respectively (notoriety, impact/benefits and associated drawback, degree of involvement, recommended investigations);
- Circuit of patients with breast, ovarian and cervical cancer in the medical system, from the first consultation until the confirmation of the diagnosis: links and the role of each medical specialist area involved;
- Main challenges that the management of breast, ovarian and cervical cancer raise for these doctors, as well as their expectations in order to improve the process.

- The “ingredients” ensuring a successful screening programme from the perspective of physicians.

The methodology for the qualitative phase of the study consisted in organizing 6 semi-structured group discussions (focus group discussion - FGD) in Bucharest, Cluj-Napoca and Iași (2 groups in each city). Gynecologist doctors and GPs respectively, were divided into separate groups in order to focus the discussion on the prospective of an individual medical specialist area, also bringing into question any possible issues that arise in the collaboration with other specialist areas. Each discussion lasted for about 135 minutes and took place in May 2016.

For the quantitative phase, a questionnaire was designed (based on the conclusions reached in the qualitative phase), which was then applied within face-to-face interviews to 204 gynecologist doctors and 225 GPs, nationally representative sample. The data collection period was 22nd August - 16th September 2016.

4.2 Conclusions from the Qualitative Study - GPs and Gynecologists

The mentions of GPs and gynecologists about the screening programmes and the management of breast, ovarian and cervical cancer are very similar, both in terms of current status, and future wishes and expectations.

Although GPs are often the first medical link the patients come in contact with, their involvement in prevention and screening is quite poor, mainly because of the very limited time for each consultation and the limited and inconsistent access to investigations, respectively; this thread of causality ultimately leads to the lack of funds, personnel and necessary equipment.

The relationship with patients diagnosed with cancer or suspected of cancer puts emotional pressure on the doctor. Thus, the ideal way of working aims for the existence of a multidisciplinary team, which would also include a psychotherapist.

4.2.1 Knowledge and Attitudes towards Screening; Recommended Investigations; Problems Encountered in Practice

Screening programmes are appreciated by all the physicians due to the benefits brought to both the medical system (in particular lower costs), and to the general population (through early detection and increased chances of being cured, thus socio-economic, family and professional reintegration).

The short-term benefits doctors mentioned concern:

- Early detection of the conditions and increased chances of being cured;
- Prevention of certain conditions to occur, through timely detection of risks;
- Access to investigation of patients with low income, uninsured or from rural areas, where access to healthcare services is difficult (e.g. in Cluj-Napoca, screening caravans were organized whereby gynecological consultations were made and smear samples were taken for the Babeş-Papanicolau test).

The long-term benefits mentioned:

- Education of the population in order to prevent the occurrence of the conditions (whatever their nature);
- Improved doctor-patient relationship (including for the young population) and the possibility to treat and control the conditions arisen with more ease before complications occur;
- Improved quality of life and extended life expectancy;
- Reduction of costs for both the patient, and the expenses within the health system.

Both GPs and gynecologists mention several screening programmes and campaigns for gynecological and breast cancers, which indicates a high level of interest for the topic.

The one that was most frequently mentioned was of course the National Cervical Cancer Screening Programme, the only one undertaken by the Romanian authorities so far.

Others have also been mentioned: “Programul Național de Evaluare a Stării de Sănătate a Populației” (National Assessment Programme of the State of Health of the Population) which, even if it did not specifically target the oncological conditions, or women, it contributed to the education of the population in order to go to annual routine check-ups (especially appreciated by GPs); as well as various regional or local screening programmes for the detection of breast cancer, organized by Oncological Institutes, private clinics or non-profit organizations.

In terms of the optimum frequency of screening investigations, physicians consider as indicated the annual screening for the detection of cervical and breast cancer, after the beginning of the sex life. Family history, as well as the manifestation of symptoms prioritize screening in the recommendations of physicians, and the start of menopause is the time when the performance of the screening becomes absolutely necessary, regardless of the patient's age. In practice, however, the investigations are carried out in most cases after the onset of symptoms.

Investigations recommended by the participating physicians:

▪ For breast cancer: breast ultrasound is recommended (for patients under 40 years) or mammography (over 40 years) yearly, even if there are no symptoms; patients with large breasts or under long-term hormonal treatment (most commonly with the contraceptives) are particularly targeted; for patients with family history the age at which mammography is required is significantly lowered; symptomatic patients (with nodules, nipple distortion, alteration of the skin, pain/bilateral breast pain, retractions that give discomfort, pain that continues after menstruation, climax disturbances) already fall under the category requiring more in depth investigations.

▪ For cervical cancer: physicians recommend annual gynecological check-up for patients with a family history, multiple sexual partners, physiological and pathological antecedents, and of course in case of occurrence of symptoms (e.g. climax disturbances), regardless of age. The Babeş-Papanicolau cytological examination is recommended annually, regardless of age or sex life debut.

▪ For ovarian cancer: abdominal, pelvic and transvaginal ultrasound yearly for patients who already show symptoms (pain, menstrual disturbances or changes, digestive phenomena, unexplained weight loss, fatigue, sexual disorders), especially if aged over 45; local blistering or ovarian cysts already indicate the need for more in depth investigations. The tumor markers CA 125 and the ROMA score may be required when there are suspicions of ovarian cancer.

In practice, physicians have noted numerous problems of screening programmes.

Both GPs and gynecologists mentioned the low level of health education of patients, leading to late visit to the doctor, as well as the low level of notoriety of existing screening programmes.

If the first aspect is a fundamental one, difficult to resolve - in Romania there is no health education in school and there is no culture of prevention - the second aspect is simply connected to the public promotion of these programmes, and thus can be resolved relatively easily by dedicated communication campaigns.

Other issues mentioned consistently by all participating physicians are related to the screening process itself. Patients are obliged to go to several medical centers, because they cannot benefit from any gratuity without referral/referrals from the GP, and the investigations themselves are not generally all made in the same place (there are very few clinics that have all the equipment and all the staff necessary to

perform a full gynecological and breast screening). Many patients are thus “lost on the way”, because they don’t have the necessary time or motivation to go through all this journey.

There are also limitations imposed by the lack of high performing equipment (nonfunctional radiotherapy devices, lack of MRI/CT devices, old and insufficient ultrasound devices in terms of numbers, especially for breast ultrasound, etc.), poor training of some physicians involved in the investigations (specialists in radiology/imaging being the most often mentioned) or the shortage of qualified medical personnel (notably oncologists). Many physicians have mentioned cases of patients denied by the oncologists they were sent them to, because they could no longer take on new cases.

Structural limitations of the programmes or the medical system in general also intervene: limiting the age threshold of patients (both in case of the Cervical Cancer National Screening Programme, and in case of regional programmes) or the lack of the possibility to carry out the annual screening within the National Programme (the Babeş-Papanicolau test may only be done once every 5 years). These structural limitations are caused mainly by under-funding of the health care system, under-funding that also influences the early diagnosis process in the absence of national screening programmes. Physicians have thus mentioned that some investigations that are absolutely necessary are not reimbursed by CNAS (tumor markers), and in case of settled investigations, the funds are often insufficient, patients being forced to wait and eventually apply for a new referral from the GP or bear the costs from personal sources.

Lack of funds is impacting to a large extent the involvement of GPs, diminishing their openness towards prophylaxis in general and towards cancer screening in particular; some of the physicians who participated in the study declared they are reluctant to refer patients to screening, to avoid the frequent situations in which the “lack of funds” is invoked, and the patients are forced to give up or pay for the investigations.

Another systemic limitation is attributed to deficient organization: there are no clear protocols guiding the patients’ circuit, which leads to great losses of time. Most patients are forced to go to several places to carry out all the necessary investigations and to establish the diagnosis.

Last but not least, even if they are specialists in oncology, participating gynecologists mentioned the lack of targeted therapies, with state-of-the-art molecules, as well,

as the standardized therapeutic approach, non-personalized; better access to testing tumor markers could be a step towards personalized therapy, with better chances of success.

4.2.2 Circuit of Patients through the Medical System

In the opinion of the participating physicians, the complexity of the patients' circuit varies by type of cancer, accessibility of investigations (in terms of price and available equipment/specialists), as well as the degree of awareness of the causes and risks of the occurrence of oncological pathologies among the female population.

GPs see themselves and are also perceived by specialists as the medical link with the greatest importance in cancer screening for women, because they are most often in contact with the patients and know best their medical history (in some cases also the medical history of the patient's family).

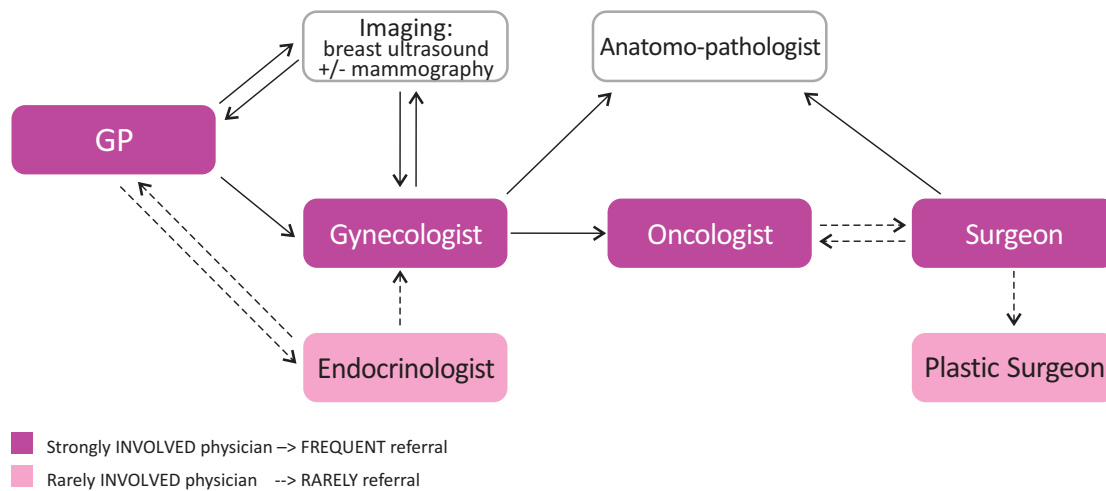
Furthermore, the GP can carry out direct palpation of the breasts or even the abdominal-pelvic ultrasound if she/he has an ultrasound and the required skills. After diagnosis, however, the role of the GP is reduced to writing prescriptions for certain categories of medicines (he/she cannot prescribe cancer treatments) and referral notes to specialists.

The gynecologist sees himself/herself and is perceived as having an important role in detecting cervical and ovarian cancer, by collecting the smear for the Babeş-Papanicolau test and transvaginal ultrasound/colposcopy, etc., although in the case of breast cancer, breast palpation can also be performed by the gynecologist. Also, if the gynecologist also has oncology competences, he/she may intervene in all stages of the patient circuit (gynecological consultation, harvesting for biopsy, surgical intervention) except for prescribing non-surgical treatment, which only the oncologist/oncology commission can do.

The anatomopathologist has an important role in identifying the type of condition: malignant or benign.

The circuit of patients with breast cancer involves visits to several medical specialist areas. Oncologist doctors and surgeons have the most important role. Gynecologists, depending on the competences they have (if they have dual specialization: gynecologist-oncologist) and the logistics they possess in the medical unit they are working in, may intervene more and simplify the circuit of patients with breast cancer.

Figure 4.1: Circuit of patients with breast cancer



Most of the times, breast cancer screening is carried out after the onset of symptoms. Patients initially go to the GP when visible or intrusive symptoms occur (breast pain, swollen lymph nodes, skin color modification, discharge from the nipple, etc.). In most cases, the GP recommends that investigations are carried out. Rarely, when the physician suspects an endocrine cause, he/she also refers the patients to an endocrinologist.

Breast ultrasound and mammography are carried out by the radiologist, less often by the gynecologist, which is sometimes a source of friction: some gynecologists complain about the fact that some GPs or radiologists misinterpret the outcome of investigations and delay the diagnosis of patients. Depending on the outcome of the investigation, the GP sends the patient to a gynecologist or directly to the oncologist. If physicians have dual specialization (gynecologist-oncologist or oncologist-surgeon), then they directly carry out the puncture-biopsy; otherwise, they direct the patient to the surgeon.

If the result indicates a pre-cancerous stage, and the formations are without malignant aspect, the gynecologist keeps the patient on record. In the event of cancer formations, the patient may be operated by the gynecologist (rarely) or directed to the oncologist. The latter recommends the therapeutic approach together with the interdisciplinary team/oncological commission - drugs, surgery and/or radiotherapy - and establishes the stages of the treatment. In Cluj there is a center specializing in breast tumors, within the Institute of Oncology.

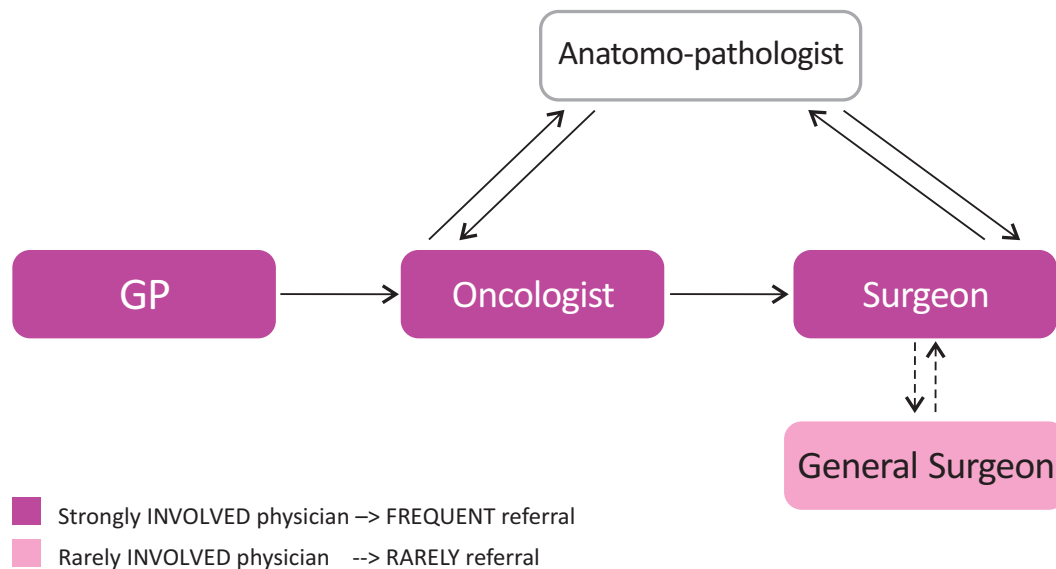
Gynecologists in Bucharest also send the patients who underwent a surgical intervention to the plastic surgeon, when possible.

The monitoring of the patient with breast cancer is carried out by the oncologist during the next 5 years (adjusting the treatment or intervening with therapeutic recommendations). Gynecologists intervene in the monitoring in case of patients with additional risks or who undergo hormone treatment.

The more reduced access to investigations (not settled or with low settlement thresholds, the lack of available equipment - especially MRI/CT) and the decreasing number of specialist doctors (especially oncologists) may delay the commencement of the treatment. Thus, in most cases, patients wait on average 2-3 months until a certain diagnosis (gynecologists in Bucharest mention a period of up to be 5 months). This period may be reduced to maximum four weeks if patients afford to pay for the investigations or if they can have them done in big centers, where physicians mention a maximum period of 4-6 weeks (or 10 days, if patients pay for their investigations).

The circuit of patients with cervical cancer is simpler, and the steps to be followed are clear, compared to the situation of the breast cancer patient. The existence of the screening programme (even if it is not accessed) has standardized in terms of procedures the patient circuit. Physicians mention that there are also patients who request on their own initiative the performance of the Babeş-Papanicolau test.

Figure 4.2: *Circuit of patients with cervical cancer*



The GP represents the main medical link in the circuit, being both the first contact point of the patients, and the one directing the patient towards the specialist. In Cluj-Napoca, some GPs directly collect the sample for the Babeş-Papanicolau test and send it to the laboratory, sending the patient to the gynecologist only if the result of the test requires it.

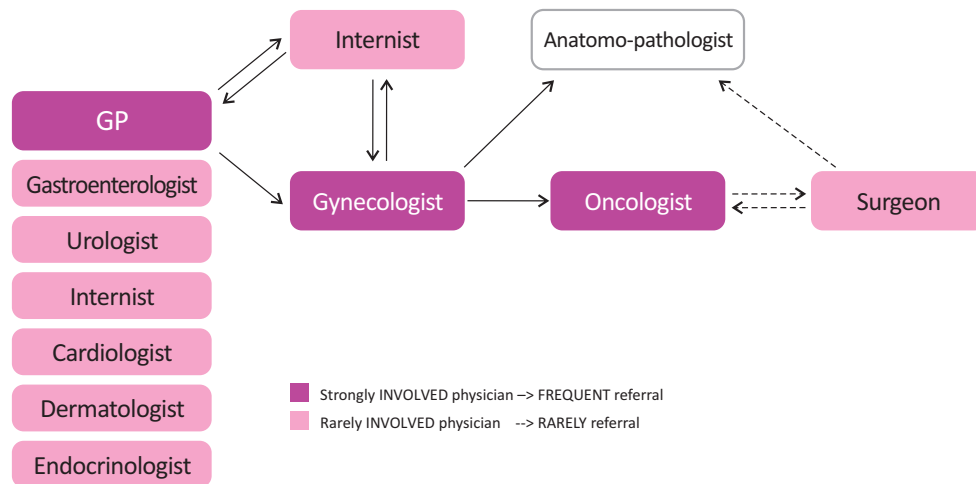
The Babeş-Papanicolau test and the transvaginal ultrasound performed by the gynecologist provide the required information for the commencement of the investigation process of the possible presence of an oncological condition. These investigations are also accompanied by a bacteriologic examination.

If the results of the Babeş-Papanicolau tests and of the transvaginal ultrasound indicate the possible presence of cervical cancer, the colposcopy and the biopsy are carried out next. This stage may be carried out by the oncologist-gynecologist or by the oncologist surgeon. Seldom, abdominal CT/ thoracic/abdominal pelvic MRI or HPV DNA genotype are recommended. If pre-cancer lesions/formations are highlighted, the therapeutic approach is led by the gynecologist. The oncologist gets involved in the management of patients in whose cases the presence of cancer cells was discovered, by surgical intervention or by non-surgical treatment (chemotherapy, radiotherapy, depending on the stage, but also availability). If *in situ*, the gynecologist also operates (performs conization in many cases).

Monitoring is carried out by the oncologist. The gynecologist has a secondary role, only getting involved in the performance of the regular gynecological examination necessary for the monitoring, if the oncologist doesn't also have gynecological competences. The GP may intervene in the management of post-radiotherapy conditions (diarrhea, cystitis, etc.).

The time from the initial visit to diagnosis is shorter: approximately 1-2 months (rarely, 3 months), because the accessibility of the Babeş-Papanicolau test is higher, compared to the mammography. If the patient is willing to bear the cost of the investigations, then the time may be reduced to 10 days, especially in the big centers, where patients may make an appointment with more ease for the investigations.

The circuit of patients with ovarian cancer challenges physicians the most, both logistically, and emotionally. The discovery of ovarian cancer is most often done by chance and in advanced stages, due to the absence of typical symptomatology and the small size of tumors, hardly noticeable in the ultrasound. The chances of healing are quite low.

Figure 4.3: Circuit of patients with ovarian cancer

In most cases, suspicion of ovarian cancer occurs following completion of the abdominal ultrasound (which may be initiated by several medical specialist areas, including by the GP). The symptoms determined by ovarian cancer can be confused with those specific to other diseases (cardiovascular, gastrointestinal, dermatological), the patient being often investigated by other medical specialist areas first. Transvaginal ultrasound represents the next step in the investigation of ovarian cancer.

If the investigation supports the suspicion, the patient may be consulted next by the gynecologist or directed towards the oncologist, if the gynecologist has no competences in oncology. For a certain diagnosis and staging the following are carried out: biopsy/histopathological examination, tumor markers, and pelvic CT/MRI respectively.

If the result indicates a cancer formation, patients are sent/remain in the care of the oncologist in order to initiate treatment. In the event the suspicion is not confirmed, patients remain in the care of the gynecologist.

Because in many cases the diagnosis is established in advanced stages, the first therapeutic step is surgical intervention (performed by the gynecologist/oncologist/surgeon). Subsequently, patients reach the oncologist/oncological commission in order to initiate the chemotherapeutic treatment.

Monitoring lies within the duties of the oncologist. Gynecologists in Bucharest also mention the introduction to palliative care centers for patients with ovarian cancer in final stages. From the first visit to the doctor, until the establishment of the full diagnosis and the initiation of the treatment, we could be talking about a period of time of 6 to 8 weeks.

4.2.3 Communication with the Patients and Interdisciplinary Collaboration

For patients, the diagnosis process means a lot of anxiety. Physicians have noticed that in most cases, patients put an equal sign between the cancer diagnostic and the risk of death. When the suspicion of this possible diagnosis arises, most patients experience strong negative emotions and feelings. Only gynecologists in Iasi also mention cases in which patients have mobilized, were proactive and determined to fight and overcome these moments.

Fear and denial of the diagnosis determine some patients to refuse the biopsy or even the surgical intervention, especially if this is perceived as a “mutilation” of the body. Physicians mention that some patients who accept radical surgery (mastectomy or hysterectomy), are trying to hide this thing from the partner, for fear that they would no longer be seen as women.

Most physicians mention that they encounter difficulties in the dialogue with patients, especially in moments of maximum emotional load. Therefore, more and more physicians are talking about the need to send patients to psychotherapy, but also courses for physicians, who would be taught how to manage such moments. Both GPs and gynecologists encounter difficulties in relating with patients, which hinders the detection and management of oncologic diseases.

GPs mention among the most important causes:

- Cultural shame related to sexual life and low levels of education, especially in rural areas, prevent patients to communicate to the physician the symptoms they have;
- Multiple resistances of patients in the diagnosis and treatment of cancer (e.g. fear that cancer cells may spread throughout the body following the surgical intervention, fear of hair loss, as a result of chemotherapy, fear of aesthetic mutilation as a result of mastectomy) and their preference for natural treatments, magnetic bioresonance and resorting to religious practices (especially in Iasi);
- Loss of contact with patients - if they do not present other co-morbidity too, it happens that patients remain in monitoring only with the specialist

Gynecologists mention:

- Difficulty of managing sensitive situations (physicians are unprepared to communicate the diagnosis, especially in the advanced stages of cancer);

- High costs for certain medical investigations required (e.g. determination of tumor markers) and reduced availability thereof (can only be made in private clinics) are a source of great frustration and even dramas, both for patients and physicians;

- Failure to prioritize cancer cases according to gravity, in order to perform the imaging investigations (Bucharest) and sometimes the treatment (radiotherapy being the most frequently mentioned) affects the management of cancer cases, both therapeutically and in terms of the physician-patient relationship.

Difficulties also arise in the relationship between the medical links involved in the management of patients with cancer. Thus, GPs mainly mention the lack of feedback: the failure to transmit information about the diagnosis and the evolution of patients back to GPs by specialist (notably oncologists, but also gynecologists). Second, there have also been mentions about the refusal of some gynecologists in Bucharest to consider the dry-based Babeş-Papanicolau test, and only the liquid-based one, this last variant not being reimbursed by CNAS.

On the other hand, gynecologists mention in particular procedural problems: inadequate smears collected by GPs for the Babeş-Papanicolau test, weak involvement of GPs in the screening and delay in the referral to a specialist. It is interesting that GPs mainly raise issues concerning the collaboration protocols, or their absence (lack of feedback, no standardization of the types of tests supported), while gynecologists mention instead mistakes in terms of medical practice.

4.2.4 Conditions of a “Successful” Screening Programme

The ideal screening programme motivates and supports the participation of both the doctors and patients. The methods by which participating doctors believe that the best participation of women can be obtained related to:

- Extensive and intense communication, both to announce the existence of the programme, and the risks of developing these cancers, and the need for periodic check-ups in general, respectively (including warnings such as “*Avoid the excessive intake of salt, sugar and fat!*”);

- Programme structure: extended addressability (no age limit), process simplicity (all investigations to be made in one place), minimizing bureaucracy (e.g. keeping the existing forms, and adding a check mark “within the screening programme”);

- Separate settlement of the screening consultation, in order to avoid the situations where the patient has no access to the programme because the settlement threshold of CNAS has already been exceeded;
- Gynecologists also mention the introduction of mandatory annual screening, by age groups, or the fining of patients who do not attend (by increasing the personal contribution to health insurance, for example);
- GPs in Bucharest also mention the increasing number of medical centers where screening can be done to avoid overcrowding: a medical center for every 20,000 people.

The methods for motivating the physicians are primarily related to the remuneration of all health professionals involved in the programme, aspect that should be clearly communicated to them in order to increase the level of interest in enrolling in the programme.

Ways to streamline the screening effort in the long term have also been taken into consideration, and also the use of the data collected during such to optimize the entire medical management system of female cancers. The physicians interviewed unanimously supported the creation of a multidisciplinary “network” (teams made of GPs, gynecologists, oncologists, doctors specializing in imaging, endocrinologists, anatomopathologists), which would be in permanent contact to decide together the best suited actions for each case without “walking” the patient between them too much.

To establish this “network”, they mentioned the condition *sine qua non* of creating a clear functional circuit: already from the enrollment of the patient in the screening programme, every link involved knows the goals that must be achieved at individual level, but also the general goals, at “team” level, and all health professionals involved can following in real time the stages the patient is going through.

It is thus absolutely imperative to create a national electronic register that each doctor can fill in with the procedures and conclusions on each patient, from the screening phase and until the monitoring after treatment. The advantages of this register would be felt not only in the management of each individual case, but also at systemic level, as it could be a source of valuable statistical data for oncology institutes, CNAS and other authorities involved in health management or financing in Romania.

4.3 Conclusions from the Quantitative Study - GPs and Gynecologists

The quantitative phase of the study confirmed the results obtained in the qualitative phase. Physicians are facing many barriers regarding the prevention and screening for breast, cervical and ovarian cancer. The low level of education, information and interest of patients, as well as the difficult access to free medical investigations (compensated by CNAS), are currently the main challenges physicians are facing in promoting prevention.

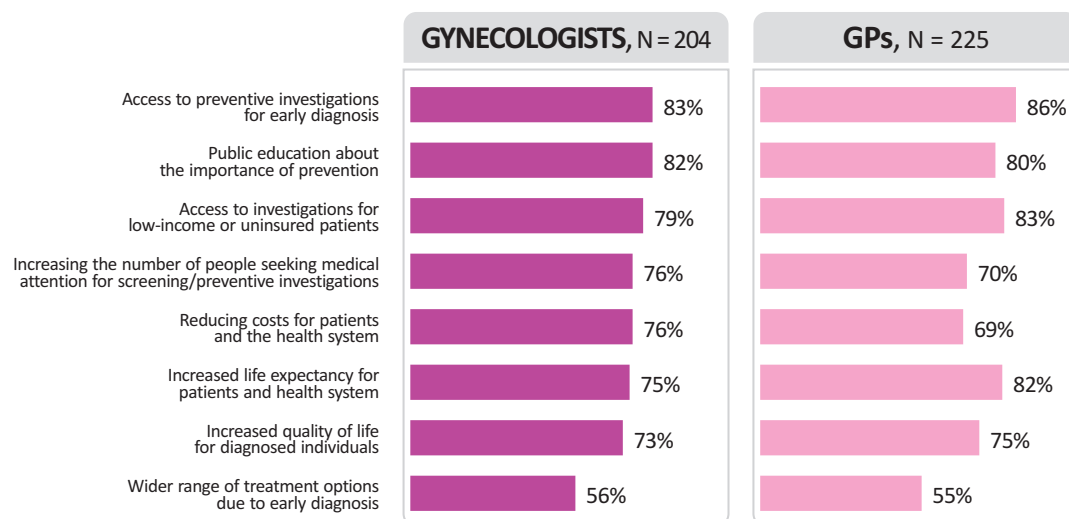
On the other hand, the management of female patients diagnosed with cancer is hindered by factors relating both to the health system (insufficient funds, personnel and equipment, lack of clear protocols to guide the patient circuit, poor coverage of medical services), and the patients (lack of health education being the main impediment mentioned).

4.3.1 Attitudes, Knowledge and Behavior related to Investigation and Screening Programmes

The opinion of participating physicians is almost unanimous regarding the screening programmes: these significantly increase the changes of diagnosis and healing of cancer in the early stages. 94% of gynecologists and 81% of GPs consider that a screening programme increases the chances of survival in a large and very large extent. The difference in percentage between the two medical specialist areas seems to come from a lower level of trust in the feasibility of screening programmes in Romania, from GPs, as we shall see hereinafter.

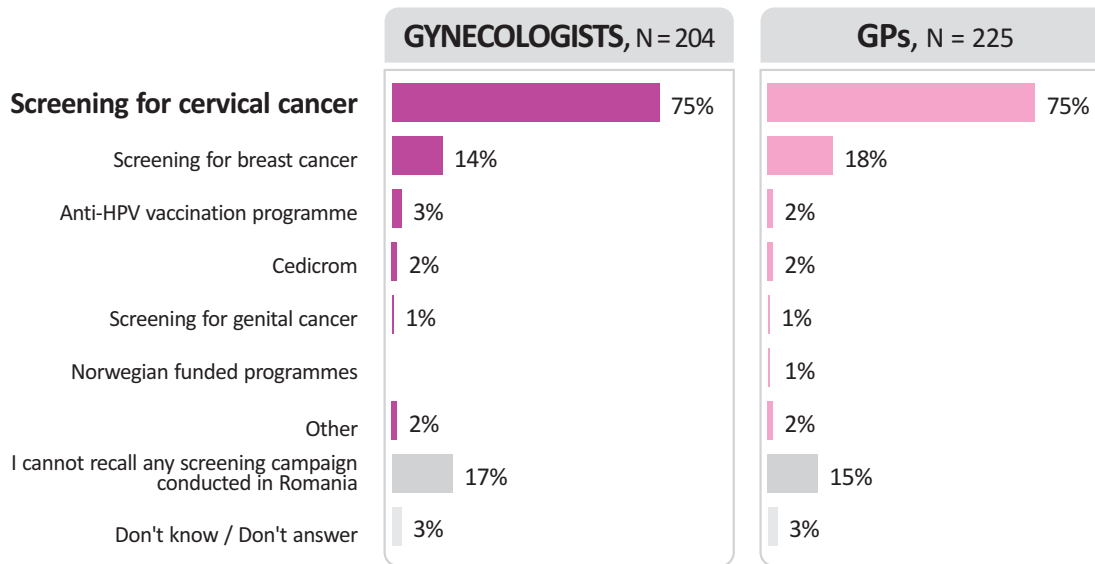
Screening programs have multiple benefits: from access to investigation and education of patients to extending life expectancy and reducing costs.

Figure 4.4: Perceived benefits of screening programmes



Asked about the screening programmes they know, both gynecologists and GPs most often mention the national screening programme for cervical cancer, which is predictable, since it is the only national programme. It is surprising that the frequency of mentions for this programme does not come close to 100%; a quarter of the doctors interviewed do not know or do not remember this programme, although it exists since 2012. The very low rate of participation of women in the screening programme for cervical cancer is thus put into a new light.

Figure 4.5: Screening programmes known in Romania



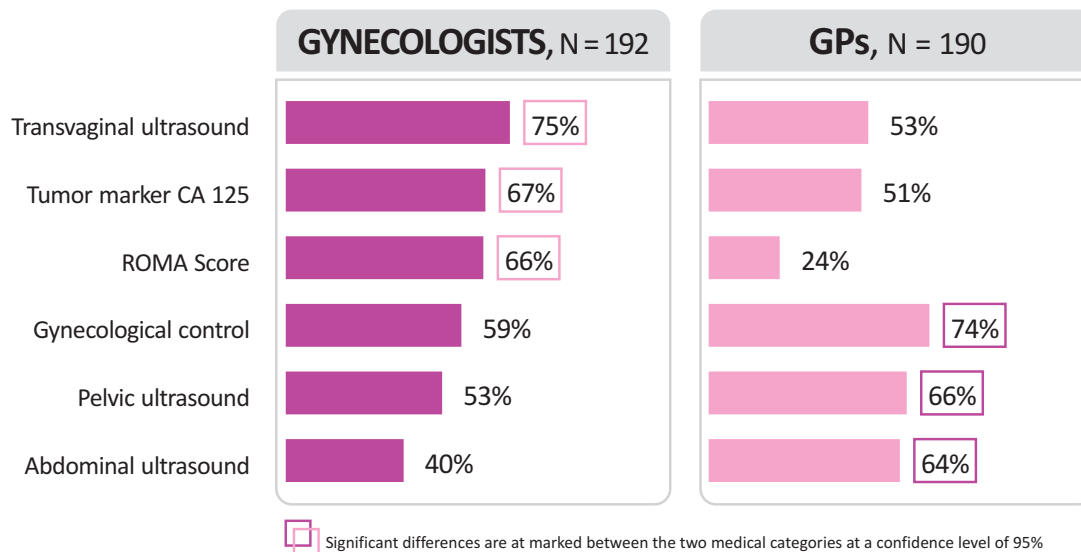
Almost all the physicians declare they perform or recommend preventive investigations to detect cancers in women: 89% of gynecologists and 95% of GPs recommend investigations for breast cancer; all gynecologists and 96% of GPs recommend investigations for cervical cancer; 94% of gynecologists and 84% of GPs recommend investigations for ovarian cancer. The type of investigations recommended by gynecologists are however partially different from those recommended by GPs, a consequence of the lack of unanimously agreed or imposed protocols. Thus, for breast cancer screening, significantly* more GPs (91%) recommend mammographies compared to gynecologist doctors, the differences no longer being significant for breast ultrasound and clinical examination (palpation).

For cervical cancer, significantly* more gynecologists (96%) recommend the Babeş-Papanicolau test, compared to GPs (87%), the latter preferring to send patients to the gynecologist (letting thus the gynecologist decide what tests to carry out, but introducing an additional station in the circuit of the patients).

*Significant differences are at a confidence level of 95%.

For ovarian cancer, there are no standard screening protocols neither in Romania nor internationally, with each doctor being thus forced to create his/her own list of investigations that he/she particularly recommends. One notes however trends, which are different from one specialization to another, as shown by the diagram below.

Figure 4.6: Screening investigations recommended for detecting ovarian cancer.



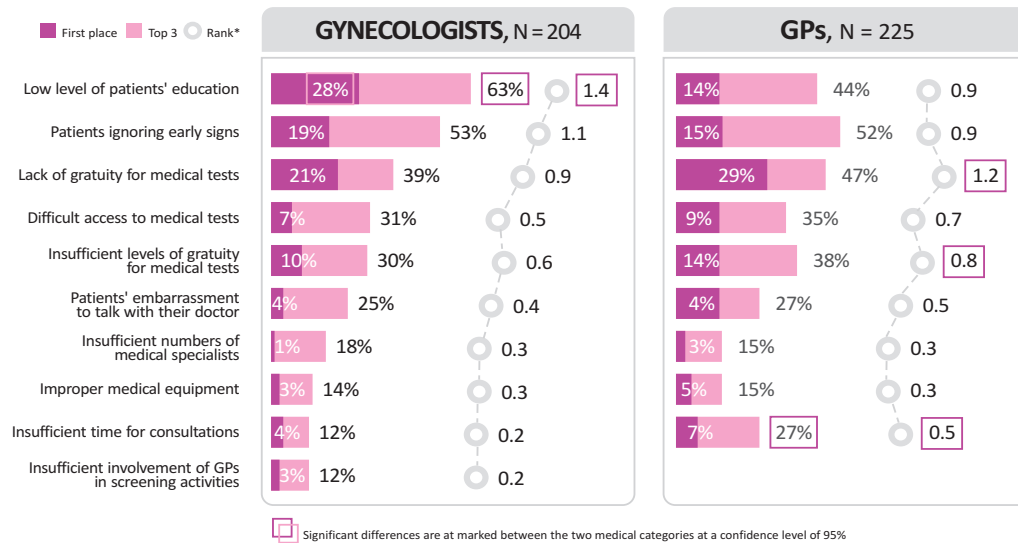
But there is a consensus regarding the responsibilities: both gynecologists and GPs believe that these two specialist areas are the main pillars involved in screening, although there are no statistically significant differences in the importance given to each specialization: gynecologists place themselves on an equal footing with GPs, while GPs give themselves more responsibility compared to the one given by gynecologists.

The explanation lies in the fact that GPs consider themselves the main responsible people for the initial investigation. In establishing the diagnosis, however, both gynecologists and GPs consider that oncologists and gynecologists play the main roles.

4.3.2 Challenges and Barriers to Screening and Management of Female Cancers

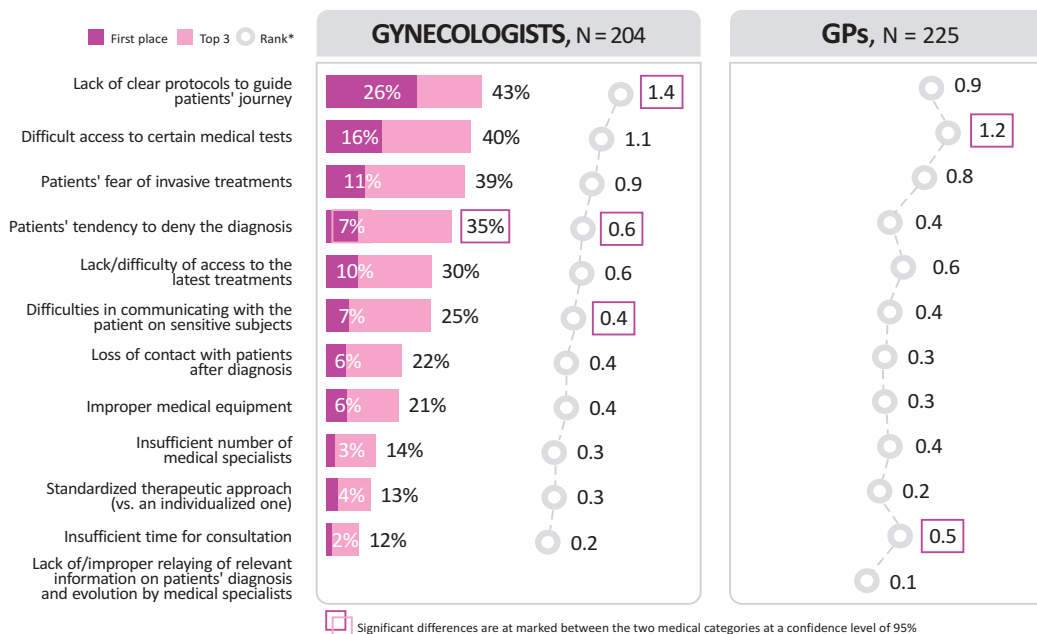
Nivelul scăzut de educație al femeilor este principala provocare cu care se confruntă ginecologii în procesul de screening al cancerului, în timp ce medicii de familie menționează mai frecvent investigațiile nedecontate de casa de sănătate.

Figure 4.7: Challenges that doctors are facing in the screening process of female cancers*



Regarding the management of female cancers, both gynecologists and GPs mention in the first place the aspects related to the logistics of the process: lack of clear protocols for the circuit of the patients through the medical system (gynecologists) and the difficult access to specific medical investigations respectively (GPs).

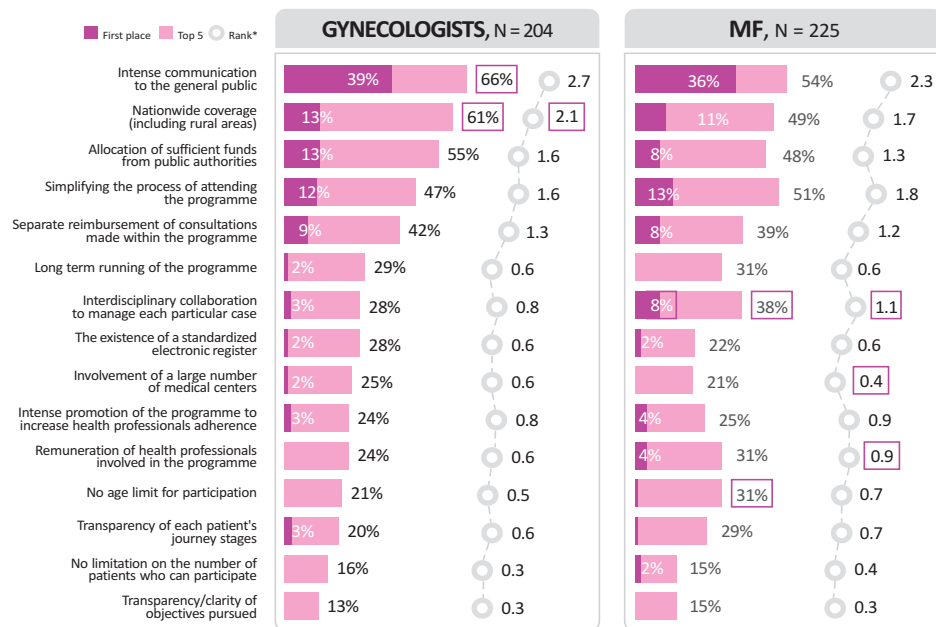
Figure 4.8: Challenges that doctors are facing in the management process of female cancers*



*The score is calculated as follows: first place received 3 points, second place received 2 points, third place 1 point in order to achieve an overall hierarchy of the claims. The score that is closest to value 3 is the one taking the claim on the first place in the hierarchy. The significant differences between the two medical specialist areas (marked with pink border) are at a confidence level of 95%.

The success of a screening campaign depends on the intense promotion nationwide and the national coverage for gynecologists, and on promotion and simplicity of the participation process for GPs, respectively. But many other factors are mentioned, the differences in frequency being generally quite small, rarely significant, which indicates that doctors understand the complexity of the conditions required to appropriately carry out a screening programme, in Romania.

Figure 4.9: Factors contributing to a successful screening programme*



4.3.3 Patients' Needs

The interaction of doctors with patients can be improved primarily through education campaigns and access to psychological counseling for patients, in the perspective of both medical specialist areas interviewed. Less importance is given to the training of the medical staff (doctors and nurses) through communication courses, indicating a shift of responsibility for the success or failure of the interaction during consultation towards the patients.

On the other hand, gynecologists and GPs unanimously agree that the reimbursed treatments available in Romania only moderately cover the needs of the patients, for all three types of cancers in question.

*The score is calculated as follows: first place received 5 points, second place received 4 points, third place 3 points and so on, in order to achieve an overall hierarchy of the claims. The score that is closest to value 5 is the one taking the claim on the first place in the hierarchy.

The significant differences between the two medical specialist areas (marked with pink border) are at a confidence level of 95%.

4.4 Conclusions from the Qualitative Study - Radiologists and Anatomopathologists

To also explore the theme from the perspective of specialist doctors involved in the more advanced stages of screening, when there are already suspicions of cancer, we interviewed 4 anatomopathologists and radiologist doctors in Bucharest. The conclusions of the interviews have no statistical validity, but allow us to take a look at the screening process beyond the “front line”, represented by the first contact of the patients with the GP or the gynecologist.

As expected, participating radiologists and anatomopathologists appreciate screening as a very efficient way to diagnose diseases (and especially cancers) as early as possible, when the chances of survival are high and the costs are significantly lower.

The essential condition that Romania is not meeting yet is the degree of coverage - doctors mentioning percentages of 70% and even 90% as the degree of coverage for the vulnerable population, with the frequency of check-ups of more than three years. So the frequency set from the outset for the national screening programme for cervical cancer - every five years - is considered inappropriate by the physicians who participated in the study. The need for a more aggressive promotion of the programme - including by means of the GPs - and proper sampling, by trained personnel, have also been pointed out, with all participating doctors mentioning that they are frequently faced with inadequate biological samples.

Among the needs still unmet of the medical system, from their perspective, radiologist doctors and anatomopathologists mention the lack of a national database, accessible to all medical specialist areas involved in the diagnosis, wherein one can fill in directly and in real time the results of the analyzes carried out, thus communicating faster and more efficiently, without wasting time with different reports.

The equipment was also mentioned by all participants, both in terms of its quality (to be modern, functional, equipped with everything that is needed) and in terms of its spread (to be enough devices in more centers of the country). Last but not least, just as GPs and gynecologists, these doctors also recognize the need for a more efficient inter-disciplinary collaboration system, in order to shorten or streamline the path of the patients from the first consultation to a confirmed diagnosis. The need to promote in the media any screening initiative, in order to mobilize the population, was also mentioned.



Chapter 5.
**THE PERSPECTIVE OF WOMEN
TARGETED BY SCREENING**



5.1 Premises and Research Methodology

In parallel with analyzing doctors involved in screening, this study aims to understand the attitudes of women regarding the screening programmes, and the barriers and challenges that they face in participating in them, respectively.

The study was structured similarly to the one on doctors, having a qualitative phase to explore the issue, followed by quantitative one to statistically check the conclusions obtained in the qualitative phase.

Thus, we can compare the attitudes and issues raised by physicians with those mentioned by the women targeted by the screening, from the age group 30-45 years, urban areas (cities with over 100 000 inhabitants). The reasons why this category was chosen are:

- It is the category targeted by all screening procedures, for all three cancers concerned, being in the middle of the most active period of life, making it unlikely to frequently go to the doctor.
- The focus on large urban areas is due to the low coverage of health services in rural areas, when there is not a lot of experience with medical services.

We have already seen the results of the „*N-am făcut destul*“ („*We haven't done enough*“) campaign - carried out by FABC in 2015 and 2016 in rural areas, we shall also be analyzing the situation based on the data collected by “*Renașterea*” Foundation.

The methodology for the qualitative phase of the study consisted in organizing two group discussions, semi-structured (focus group discussion - FGD) in Bucharest and Iași (one group in each city). Each discussion lasted for about 135 minutes.

For the quantitative phase, a questionnaire was designed (based on the conclusions reached in the qualitative phase), which was then applied within face-to-face interviews to 424 women, nationally representative sample. The data collection period was 7-16 September 2016.

Table 5.1: Distribution of participants to the study depending on the size of the city of residence

Size of city (thousands of inhabitants)	No. of participants	%
Bucharest	128	30%
100-199	115	27%
> 200	181	43%
TOTAL	424	100%

Table 5.2: Distribution of participants per regions

Region	No. of participants	%
Bucharest	128	30%
Moldova	79	19%
Transylvania	58	14%
Muntenia	45	11%
Oltenia	35	8%
Banat	30	7%
Crisana-Maramures	28	7%
Dobrogea	21	5%
TOTAL	424	100%

Table 5.3: Distribution of participants depending on occupation

Occupation	No. of participants	%
Permanent job	372	88%
Housewife	20	5%
Temporary job	15	4%
Maternity leave	7	2%
Unemployed	5	1%
I don't work for other reasons	5	1%
TOTAL	424	100%

5.2 Conclusions

Although they consider cancer to be a serious disease, the interest of the general population in screening is low. Cancer is regarded as one of the most severe diseases possible, because of the risks it presents, the strong impact both physically and emotionally (due to the side effects caused by the treatment, as well as the damage to self-image) and not least, the issues of social reintegration, particularly for breast cancer - the perception of “mutilation” generated by the loss of the breast.

Despite this perception, the general population is very little involved in prevention and routine check-up. Women resort at most to the gynecological check-up, possibly the Babeş-Papanicolau cytological examination, but only upon recommendation from the doctor or when a close person is diagnosed with cancer.

5.2.1 Definition of Health Status; Attitudes towards Prevention and Screening

In most cases, the health status is viewed optimistically and placed in a close connection to emotional balance and a healthy lifestyle (proper nutrition, physical activity, etc.). For most women, though, the lack of symptoms is equated with a good health status.

Women mention similar ways of maintaining health, but also that these are rather theoretical options, which do not reflect concrete actions. These are, in order of perceived importance:

- Positive thinking, lack of stress;
- Appropriate diet;
- Sufficient hours of rest (~ 8h of sleep);
- Detoxification diets;
- Sport, walks in the park;
- Adequate hydration;
- Avoiding products containing colorants or preservatives in excess;
- Regular check-ups and carrying out periodic medical investigations are mentioned spontaneously, but not among the first measures to take to prevent the deterioration of the health status. However, women mostly resort to these in most cases only after the occurrence of the symptoms.

However, most women in Bucharest declare they go to the doctor for a general check-up on a yearly basis (most often they take advantage of the free general investigations). The visit to the doctor for specific investigation is done in most cases when symptoms become more acute. However, there are also situations in which women go to the doctor for routine investigations (especially in Bucharest), determined by the gratuity/obligation to perform them (occupational medicine examination), the insistence of close people or easy access to the medical act by the provision of private healthcare offered by the company they work for. A special situation is the preparation for a possible pregnancy, when the attention paid to health is increased.

The most commonly performed investigations are blood tests (at the recommendation of the doctor), ultrasound examinations (abdominal or breast ultrasound, but after the appearance of lumps is observed) and the Babeş-Papanicolau test (carried out only upon the recommendation of the doctor).

About mammography, women know that it is recommended after the age of 40-45 (but most respondents in this age group do not comply with the recommendation). The HPV test was mentioned only by a few respondents, who also know its role.

The main reasons women do not carry out screening investigations are related to low levels of medical education, that respondents recognize; the low involvement of physicians in informing patients (women mention that, many times, GPs do not encourage medical visits for preventive purposes, probably because they cannot handle the large number of patients) or even the unprofessional approach of some physicians (arrogant attitude, lack of courtesy or consideration for the patient and her need of being informed about the disease & treatment); the high cost of investigations (which are either not reimbursed, or the settlement involves very long waiting periods) and, not least, the inefficient and complicated medical system (appointments that are hard to set, long waiting times in clinics, trips to several medical centers for a single package of investigations, erroneous results). The absence of clear symptoms, stressful lifestyle, lack of time and multiple problems to be solved can lead to neglecting health and sometimes even ignoring the symptoms. The fear of a possible oncological diagnosis makes many women postpone the visit to the doctor.

In general, what arouses most interest in women for carrying out the investigations for preventive purposes is direct contact with people diagnosed with cancer (friends, relatives, colleagues).

Other factors that can increase the interest of women for screening are:

- Accessible costs of medical examinations (ideally: packages of investigations at convenient prices);
- More involvement from doctors, both GPs and specialists (more recommendations and clear directions towards centers where several types of investigations can be carried out);
- A sistem mai eficient, în care personalul medical să se implice în programarea pacienților la consultații de screening, iar orarul programărilor să fie respectat (astfel evitând cozile interminabile la ușa cabinetului);
- Facilitation or even obligation of screening for these types of cancers as part of periodic occupational medicine examinations;
- Last but not least, the promotion of screening programmes with strong emotional impact (even negative) - a suggestion agreed upon especially by respondents from Bucharest.

Stimulating openness to screening is associated with long-term benefits, both at individual level - increasing life expectancy through early diagnosis - and socially - reducing the costs from the state budget for cancer treatment.

5.2.2 Associations and Level of Knowledge regarding the Investigation, Diagnosis and Treatment of Female Cancers

According to respondents from the female general population, breast cancer is the widest spread oncological condition affecting women, but also the easiest type of cancer to identify. Respondents correctly mentioned most specific signs: nodules, pricks in the breast area, presence of certain secretions, breast pain. They have also correctly listed the investigation methods: self-examination of the breast, breast ultrasound (carried out when self-palpation indicates nodules), mammography (known only in theory, none of the respondents having any direct experience of a mammography).

Respondents also correctly mentioned the most specific signs of cervical cancer: bleeding outside the menstrual cycle or after the start of menopause, HPV presence (although none of the respondents had done the test for detecting viral strains), abnormal secretions. The investigation method mentioned is also correct: the Babeș-Papanicolau cytological examination, but again, only theoretically, as in reality most respondents had never done it, a few having only done it once in their life.

The listing of specific signs of ovarian cancer was less secure, many respondents saying they know nothing about this type of cancer. The list of symptoms mentioned include repeated colds, anxieties, these two symptoms having in fact no relation to ovarian cancer, and the presence of cysts that can develop into a malignant form. Hormonal imbalances, infertility or other symptoms that may be associated with this type of cancer were not mentioned.

The investigation methods listed:

- Gynecological examination, considered, theoretically as recommended every 1-2 years in the absence of symptoms; but in practice the interval at which women have it done it is much greater;
- Transvaginal ultrasound, which is however not carried out for preventive purposes, especially due to the high costs;
- Simple pelvic ultrasound, carried out particularly when some symptoms occur.

Openness towards medical information is high. However, the search for information in the medical sphere is performed when symptoms develop or when a close person is facing a health problem. The most accessible sources of information for women are:

- Internet - the first source of information accessed, being the most handy, even if it is not considered the most credible;
- Doctor (GP or specialist) - the source invested with the highest level of confidence;
- Friends and acquaintances - especially if they have already “been through” similar health problems;
- Pharmacist – to whom they resort when interested in minor problems;
- Information presented in TV shows are particularly appreciated in Iași.

For the improvement of the level of knowledge, participants asked for the development of communication campaigns emphasizing the risks that they assume if they do not carry out regular investigations or fail to take preventive measures, and what these are; the lists with the centers where one can carry out investigations or treatment (location, working hours, contact) should also be published.

In the view of respondent women, the presentation method of this information should be accessible and friendly, engaging: short videos presenting possible symptoms announcing the presence of cancer, possible causes of this disease, available treatments and

medical specialist areas they should be addressing; short messages in the form of recommendations (similar to those presented during TV commercial breaks - a measure also mentioned by physicians); flyers/brochures containing information about the steps they need to follow. Furthermore, the sources of information should be vast and easily accessible: media, internet, medical practices (especially family medicine), pharmacies, etc..

5.3 Conclusions from the Quantitative Study

Women in urban areas, aged 30 to 45, consider that a good health status is characterized by the absence of serious diseases and a general good state, thus equating the lack of symptoms with health.

Specialist investigations are more rare, most visits to the doctor stopping at the GP's office. He/she is considered, in fact, the most reliable source of information on medical issues, which recommends his/her involvement in the information campaigns on screening programmes.

Half of the women in the target age of 30 to 45 have never heard of the existence of screening programmes and only 6% have ever participated in such evaluations. However, it is worth noting that screening programmes are met with openness and are generally appreciated as increasing the chances of survival. The main barriers to accessing screening programmes are lack of information and perceived costs (in terms of money and time).

Breast cancer is recognized as the most common type of cancer among the female population. Most women are properly informed about the key signs, examinations and investigations recommended. However, these medical evaluations are not very common among women, an aspect that is also valid for the other types of cancers analyzed in this study.

5.3.1 Definition of Health Status

A good health status is best reflected by the absence of serious diseases and a general state of wellbeing. Women from Moldova rely more on a good emotional, professional, family (38%) balance and less on physical well-being (13%) in defining the concept of "good health status", compared to women in other regions.

Avoiding stress, balanced diet and rest help maintain a good health status. About half of the women declare they respect the principles of a healthy lifestyle.

5.3.2. Associations and Level of Knowledge regarding the Investigation, Diagnosis and Treatment of Female Cancers

The 3 types of cancers under scrutiny are spontaneously mentioned by all women, being the most known and considered the most widely spread: breast cancer - 93%, cervical cancer - 67%, ovarian cancer - 47%.

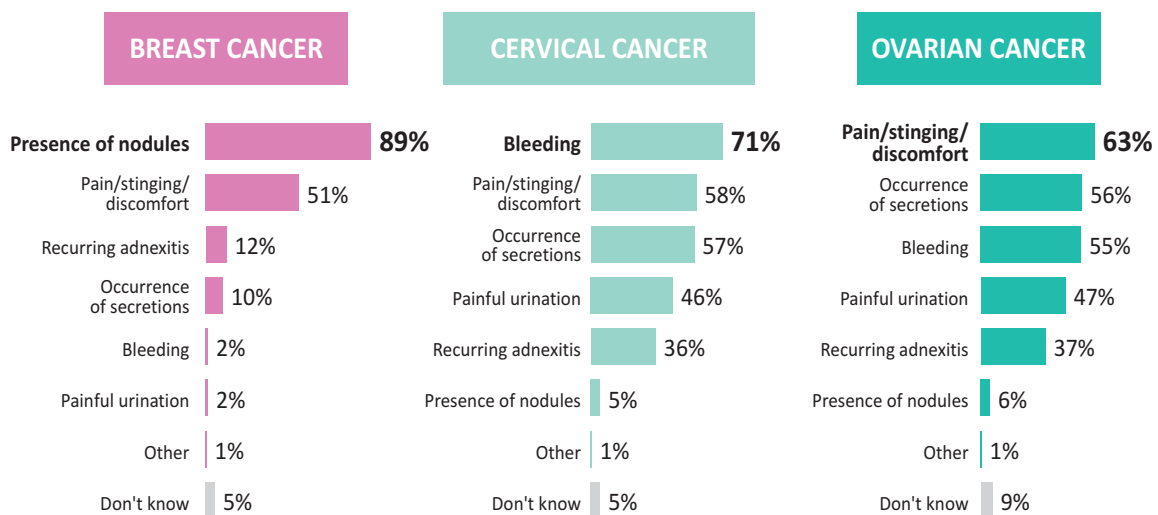
Women in Oltenia and Banat-Crișana-Maramureș, mentioned significantly more often breast cancer and cervical cancer (97% and 88% respectively).

Regardless of the type of cancer, 4 out of 10 women have at least one acquaintance affected by one of the three forms of cancer: 3 out of 10 know someone affected by breast cancer; 2 out of 10 know a person affected by cervical cancer; 1 out of 10 know a patient with ovarian cancer.

In terms of the gravity of the disease, cardiovascular diseases, hepatitis C and HIV/AIDS are perceived, on average, as having a similar degree of severity as breast, cervical or ovarian cancer, while diabetes and hepatitis A and B are perceived instead as being more severe.

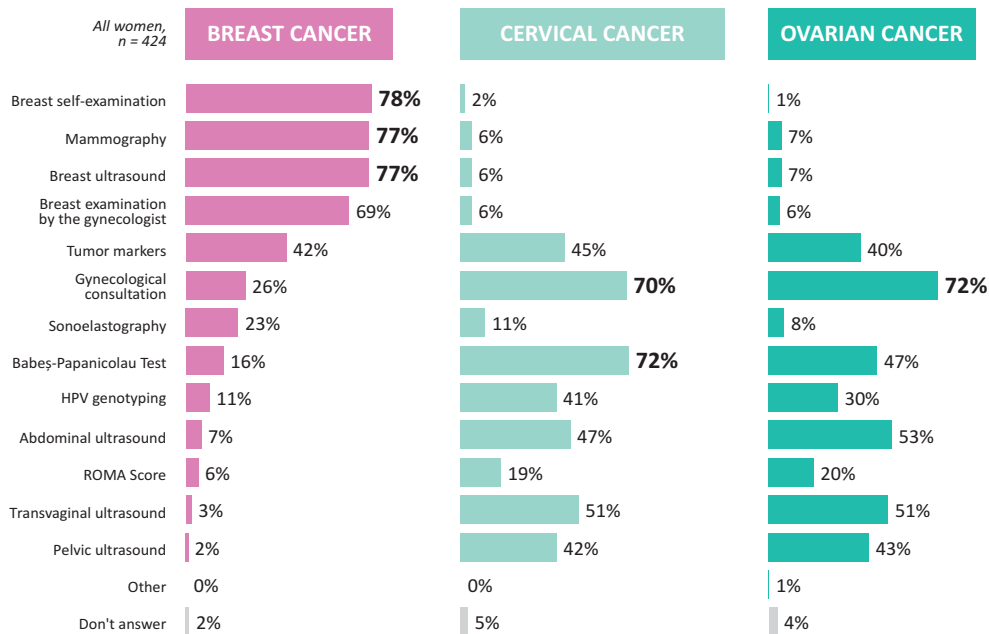
The main signs of cancer known (also mentioned by respondents in the qualitative phase) are nodules (breast), bleeding (cervical) and pain/localized discomfort (ovarian).

Figure 5.1: Main known symptoms of the three types of cancer



Most women are aware of the main investigations necessary in screening for breast, cervical and ovarian cancer.

Figure 5.2: Main investigations known for each type of cancer

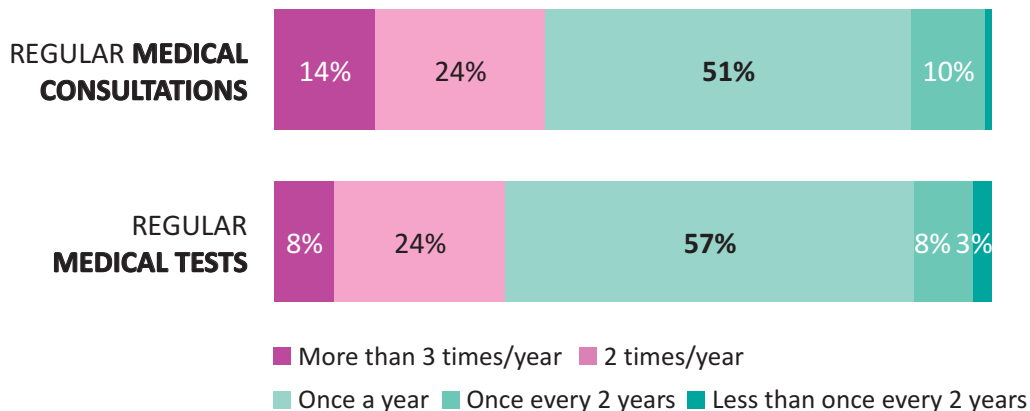


It is interesting, though, that this rather high level of knowledge does not transform into a correct behavior from a medical standpoint, as we shall see further on in this document.

5.3.3 Attitudes and Behaviors towards Prevention and Screening

Only 31% of women carry out regular medical investigations, while 42% declare they regularly go to the doctor for routine consultations. The frequency of performing these investigations or consultations also varies a lot.

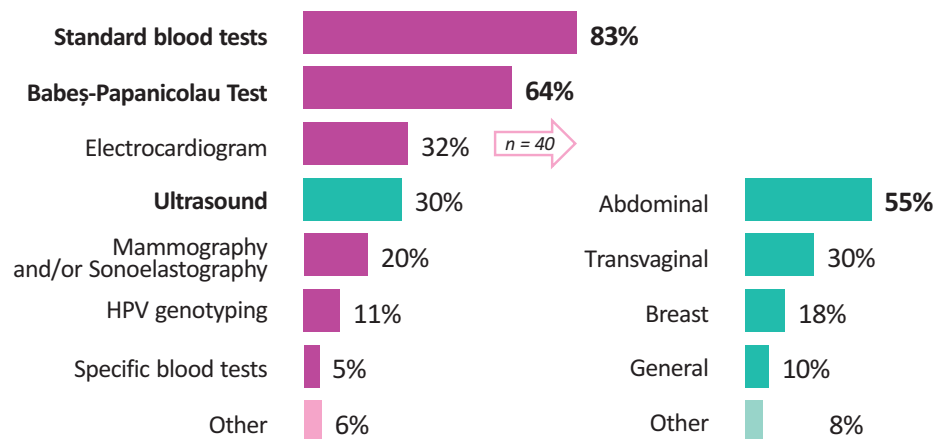
Figure 5.3: Frequency of check-ups, and investigations carried out periodically



On average, women visit 2 medical specialist areas on a regular basis; most women address the GP and the gynecologist. In Bucharest there are significantly more women who go to the dentist regularly (48%).

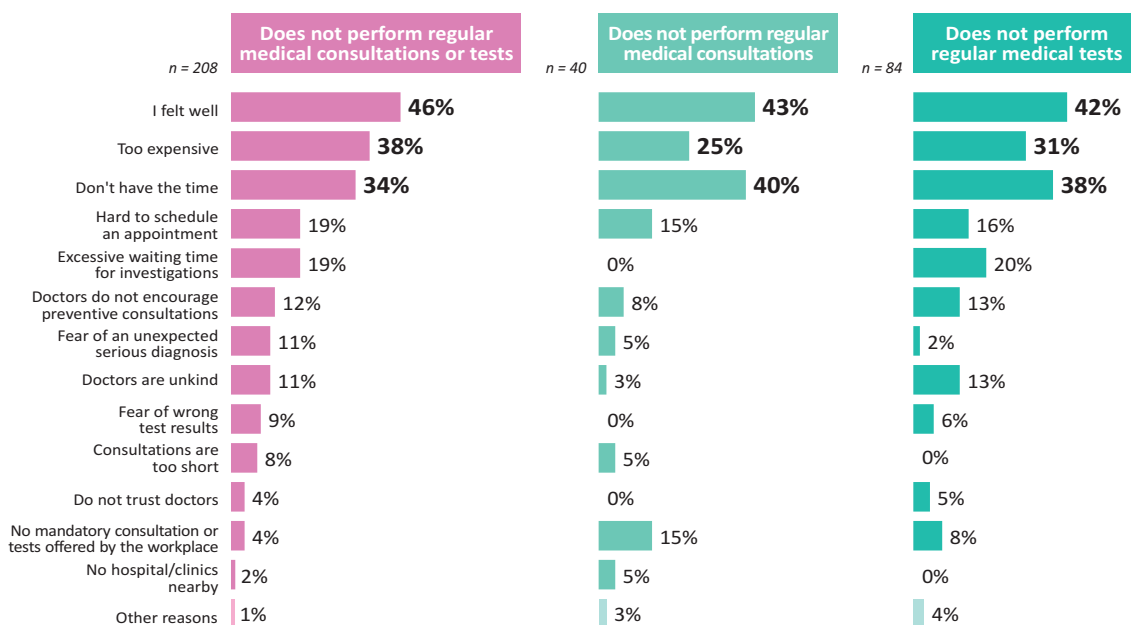
Women in Transylvania go less to the GP (64%) compared to the rest of the country, while all women with low education are addressing the GP. In terms of the investigations carried out, the most frequent ones are blood tests and the Babeş-Papanicolau test - note, however, that the reporting base for the percentages in the chart below is low (31% of women carry out periodic medical investigations), so in relation to the overall population, it results that only about 20% of women carry out the Babeş-Papanicolau test, a percentage close to the low level indicated by national statistics (17%).

Figure 5.4: Type of investigations performed periodically



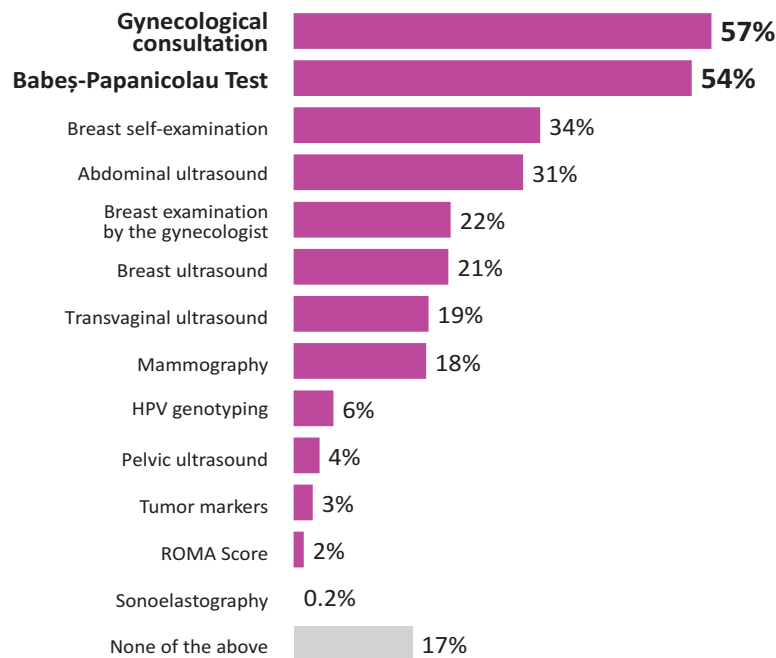
The absence of visible symptoms, high costs and lack of time are the main reasons discouraging visits to the doctor. Organizational barriers are also not to be neglected: the difficulty in obtaining appointments and long waiting time.

Figure 5.5: Reasons for which periodic medical check-ups/investigations are not carried out



Despite quite a good level of knowledge on the need for periodic check-ups and types of investigations necessary, this knowledge does not stimulate a responsible behavior. For example, self-examination of the breasts - the most commonly recommended and found completely under the control of women, without requiring the involvement of a doctor - is only a habit for a third of women, while the gynecological examination and the Babeş-Papanicolau test are carried out by just over half of respondents. Other types of check-ups and investigations necessary for early detection of the three types of cancers targeted by the study are carried out by less than a third of women.

Figure 5.6: Main investigations carried out

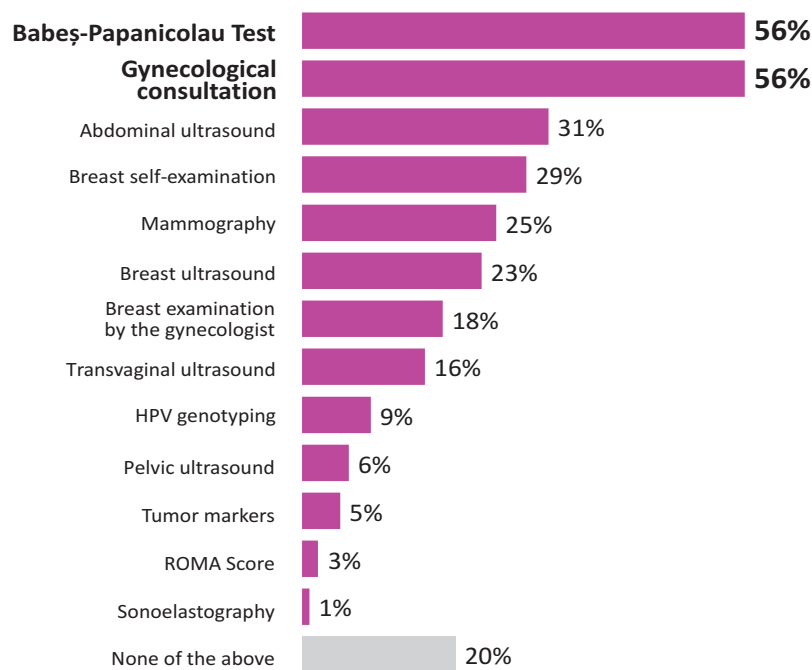


The Babeş-Papanicolau test was carried out to a greater extent by women with income > 2,500 lei (80%) and high education (65%), and to a lesser extent by women with low education (35%).

Another aspect to note is the disparity between the statements of doctors and those of women in the investigated population, in connection with the recommendation of screening investigations. While 9 out of 10 doctors were declaring they recommend screening investigations to patients, a fifth of respondents declare they have received no recommendation from the doctor for the detection of cancers, while the frequency of recommendations for different types of investigations is much smaller than we expected. It is possible that women do not remember the recommendation (especially if they have not adhered to it), or that they do not want to mention it (although the anonymity of responses was ensured). But it is equally possible that the statements of doctors were

conforming to the expectations for a “correct” professional behavior. Note that during the qualitative phase too, many women mentioned that some doctors (especially GPs) would not encourage consultations and investigations in the absence of symptoms, probably (the respondents consider) due to over-loading of the medical personnel is feeling, and the healthcare system overall (especially in terms of the procedures reimbursed by the health fund). In the absence of patient registers that include both the medical recommendation (referral), and the procedures performed, the truth is difficult, if not impossible to know. But the result remains: very few women in Romania take medical actions (consultations, investigations) to facilitate the early diagnosis of cancer, or other gynecological and breast conditions.

Figure 5.7: *Investigations the participants have received medical recommendations for*



Women in Bucharest declared that doctors recommend to them gynecological check-ups to a higher extent, while women from cities < 200 000 inhabitants were recommended medical investigations to a lesser extent, in general.

5.3.4 Level of Knowledge and Access to Existing Screening Programmes

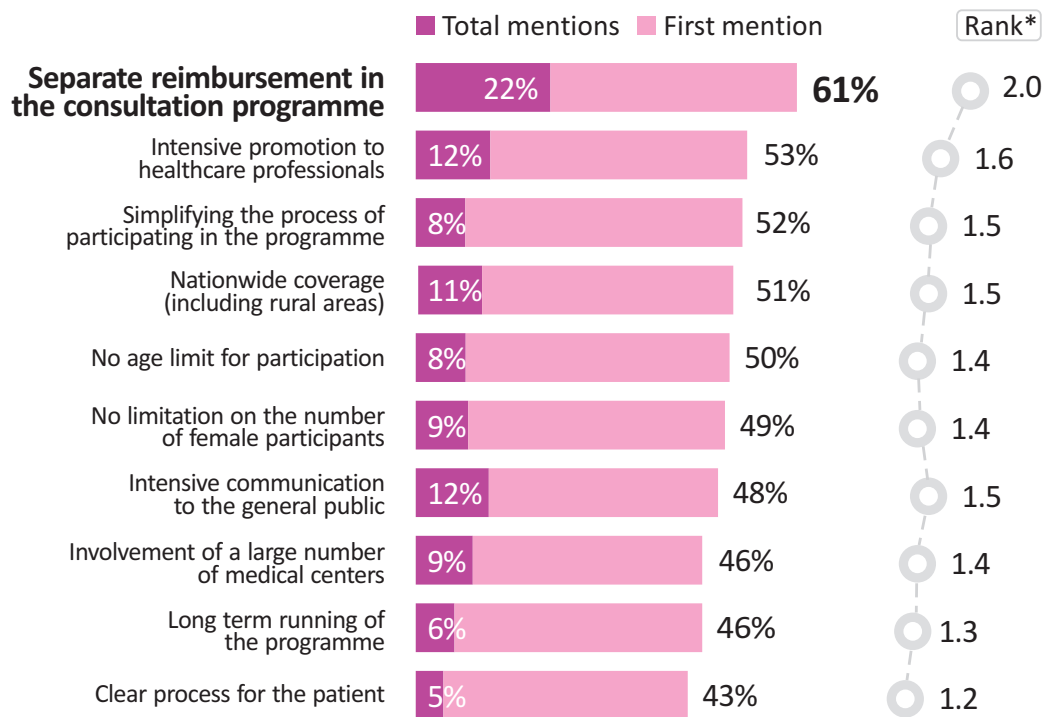
There is a widespread belief that screening programmes increase chances of survival, 85% of respondents considering that the impact of screening is high and very high. Despite awareness of the importance of screening, 52% of women are not informed regarding the existence of screening programmes. Of those who declare they have heard about at least one programme, only 28% mention spontaneously the programme for cervical cancer (13% of the total population),

while 49% (24% of the total population) failed to mention any programme, though initially they declared that they had heard of the existence of screening programmes in Romania. This largely explains the extremely low rate of participation in screening; more difficult to explain is why they did not hear about it at least in the recommendations of gynecologist doctors and GPs, who are up to date with the existence of the national screening program for cervical cancer in proportion of 75%.

Of the women who declared they had heard of the existence of screening programmes, only 12% (6% of the total population) have also participated in such programmes, most stating that they participated in the screening programme for cervical cancer, the rest mentioning various temporary or local programmes for breast cancer*. Of the 88% who have heard of the programmes, but did not participate in any of them, 59% go on their own to carry out check-ups or medical examinations, which is suggestive for the ease of access and attractiveness of screening programmes in Romania.

This brings us to the discussion of the conditions necessary for a screening programme to be “successful”, according to women. The most important aspect for them is access to free of charge consultations within the programme, followed by promotion to doctors and ease of access (the simplicity, greater coverage in terms of geography/regional, age, conditions of participation). The promotion to the large public is also not to be neglected.

Figure 5.8: Conditions required for a “Successful” Screening Programme*

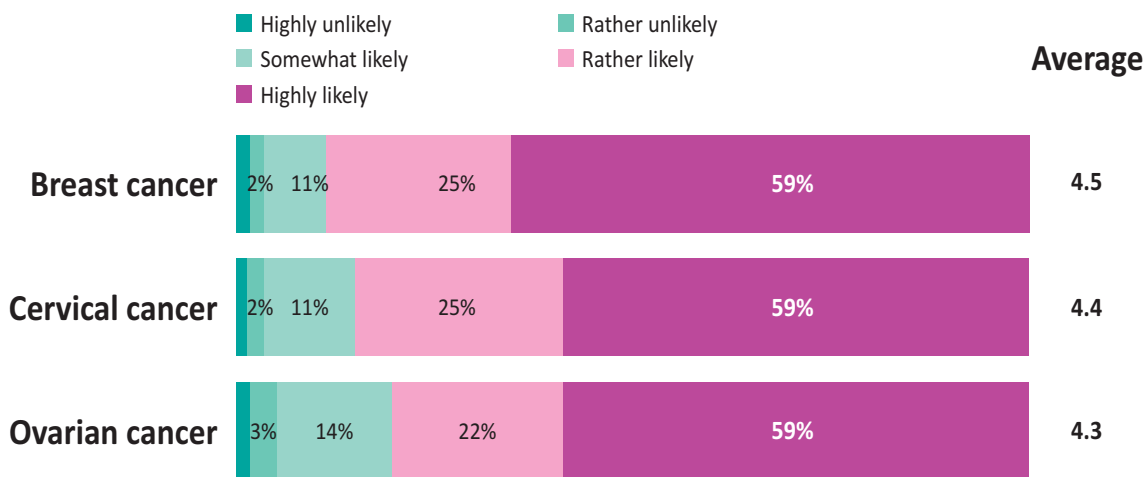


*Percentages no longer matter in this case, because the reporting base is too small to be significant.

There are high expectations regarding the involvement of authorities and doctors in the organization and promotion of screening programmes they can trust: 77% of women mention the Ministry of Health, 72% mention specialist doctors, 71% of them mention GPs respectively, and 67% mention the National Health Insurance Fund.

Despite discouraging participation rates, women show a lot of openness (at least on a declarative basis) for the participation in screening programmes, if these had all the attributes they have indicated as important.

Figure 5.9: The possible level of participation in the screening programmes that meet the conditions required for being “successful”



5.3.5 Sources of Information on Medical Topics

Unlike the results obtained in the qualitative phase, the quantitative testing revealed that the source of information that is most widely spread on health is represented by the GPs (mentioned by 83% of respondents), followed at a distance by relatives/friends/acquaintances (43 %) and the internet (41%).

Specialist doctors were mentioned by only 26% of respondents - of these, gynecologists ranking on first place (89%). The GP is also invested with the highest trust rate (71%) among the various sources of information on health issues. It thus becomes very obvious the importance of GPs as educators and promoters of “healthy” behavior.

*The score is calculated as follows: first place received 5 points, second place received 4 points, third place 3 points and so on, in order to achieve an overall hierarchy of the reasons. The score that is closest to value 5 is the one taking the reasons on the first place in the hierarchy.

There is a wide opening on information about gynecological and breast cancers (83% of women declaring themselves interested), the early symptoms of cancer generating the strongest interest (80%), followed by investigations and detection methods (69% and 67% respectively), causes (65%), treatment methods (58%) and medical specialist areas that should be consulted (53%).

5.4 Statistical Correlations Based on Data Collected from the Investigation and Diagnosis Centers

“Renașterea” Foundation operates 2 centers of diagnosis in Bucharest, and in order to also cover rural areas, the Mobile Unit of the Foundation annually organizes testing caravans in the areas with low access to medical screening for breast and cervical cancer, as well as other gynecological diseases.

Based on data collected by the Foundation in its centers, as well as in the testing caravans, a few interesting statistical correlations can be worked out, the calculation basis being very large - over 5000 patients.

Thus, we note that the unit where the testing was conducted is relevant for the frequency with which women in the sample resorted to mammography. Women who resorted to the Bucharest center “Șerban Vodă” have the highest chance of having less than 1 year from the last mammography, compared to other categories of women in the sample defined by the place where the test was carried out. The mammography tests carried out in 2016 with the Mobile Unit included the largest category of women in the sample who declared three years or more (also including here the category “never”) since the last mammography.

The absence of other correlations is significant for the lack of medical education, which in this case is “translated” into lack of awareness of the risks. Thus, the risk due to the existence of 1st degree relatives diagnosed with breast cancer does not seem to generate a more intense prevention behavior, through more frequent check-ups - according to the sample data. Nor do the debut age of the menstrual cycle or its regularity - both being risk variables for all 3 types of cancer examined.

But there are significant correlations between older age (over 60 years) and submission to invasive procedures - biopsies or even surgical interventions - suggesting that women nevertheless go to the doctor when symptoms become obvious, but not before.



Chapter 6.

**THE PERSPECTIVE OF THE PATIENTS, CURED OR
UNDER TREATMENT, AND OF THEIR DEPENDENTS**



6.1 Premises and Research Methodology (Qualitative Study)

Among the categories of persons involved in or affected by the management of cancers in Romania, patients and their families (dependents) certainly represent the most important category, both in terms of the impact the disease and treatment has on them, and in terms of their direct experiences, whereby solutions can be drawn to improve the system.

To understand the perspective of patients and dependents, 17 face-to-face interviews were held, in Bucharest, Iași and Cluj-Napoca, during the summer of 2016. The qualitative solution was preferred because it allows for in-depth exploration of the experiences of those interviewed, and also because the emotional load of the discussion was thus managed better (which would not have been possible in the application of a questionnaire). The conclusions arising from this component of the study are not statistically significant, but bring out details hitherto unexplored regarding the issues of the medical system, but also the psychological, family, financial and social impact of female cancers.

6.2 Conclusions of the Study

Cancer is viewed by patients and dependents as a serious disease, with a negative impact on all aspects of their life. In theory, a good disease management requires teamwork, whereby both the medical personnel and patients and their families contribute, in a relationship based on trust and professionalism. From the experience of the patients, however, this objective is far from being reached or even feasible at this time.

The experience of the battle with cancer evokes different moods and meanings to patients and dependents: while most patients are trying to mobilize and be strong (even if it means a struggle with oneself), dependents feel pessimistic, powerless witnesses to the drama of the patient, the family, but also their own personal drama.

The impact of cancer is felt in all aspects of life. In most cases, relationships with family members have improved. At the same time, patients (particularly those who have recovered) become more assertive, more careful at their lifestyle and sometimes even trying to “convert” other women to a healthier lifestyle and a preventive behavior (including regard periodical medical check-ups). However, some of the patients mention a deterioration of their emotional state (they are still sad,

cautious, nervous), self-image and couple life (due to the physical and psychological marks left by mastectomy, hysterectomy or other treatment procedures, such as chemotherapy). All tend to become more selective in choosing friends and more focused on their own needs.

For patients who are still fighting with disease, social life is often negatively influenced both by the physical and mental suffering, and the marginalization attitude of those around. Thus, social relations are more distant, with a rigidity in the interaction existing on both sides.

From a financial standpoint, the biggest sacrifices are in the diagnostic phase, in order to cover the investigations carried out in the private system. In general, financial difficulties decrease with the completion of the chemotherapy/radiotherapy treatments, because frequent trips to the doctor or treatments to fight the side effects of the cancer therapy are no longer necessary. For patients who retired as a result of the illness, revenues fell dramatically, so that they now need financial support from their partner or family.

The circuit of cancer patients is rather difficult, the biggest drawback being the lack of information on the steps that they need to go through once diagnosed: necessary investigations, the possibility that these are compensated, medical specialist areas involved, necessary treatment and its side effects, information on mastectomy/hysterectomy, etc.

There are also delays in the diagnosis and the initiation of therapy, due to late presentation of the patients to the doctor, the misinterpretation of investigations or under-diagnosis and limited resources of the state medical system.

Throughout the circuit, but especially in the stage of diagnosis and initiation of therapy, both patients and dependents need information and moral support.

Patients have mostly felt the need for:

- More clarity regarding the steps to be taken, and the compensation they can benefit from in performing the investigations, respectively;
- More medical personnel involved, having a proactive and professional attitude;
- Better organization of medical centers, so that the investigations can be carried out in the same place;
- Decent hygiene and hospitalization conditions;

- Access to psychological support within the hospital/clinics, both for patients, and for dependents;
- Counseling regarding the rights they have at work/for retirement.

6.2.1 The Experience with Cancer: Personal, Family, Social Impact

Cancer patients fight a daily battle against the disease, the states of helplessness, frustration, sadness, and sometimes the feeling of loneliness. In the face of uncertainty about the future, the feeling of lack of control and despair, there is also the risk that patients lose trust in the physician, the treatment or the prospect of healing, but they can also actively participate and develop a partnership with the doctor to fight against the disease.

Fighting cancer is a long story, involving many types of emotions, and it is hard to put into words. The moments of increased psychological impact were finding out the diagnosis and the period of chemotherapy treatment. The emotional load reaches maximum peaks when the self-image deteriorates after mastectomy or hysterectomy, loss of hair, etc., often accompanied by depression. But it is representative of all patients interviewed that this experience, which debuted as a drama, became an adventure once the disease was defeated.

In turn, dependents fight their own battle with fear, frustration, panic and the refusal to accept that the loved one is facing this health problem. States of frustration, fatigue, burden appear when female patients become self-centered, demanding, uncooperative.

The relationship of patients with family members/partner has become tighter in most cases, because patients feel/felt support from the family and the life partner.

However, sometimes patients have chosen to hide the illness they are suffering from, from the family (due to care towards them and fear of not affecting them strongly) or they themselves are the ones protecting and managing the drama of the entire family, because there are no other support systems. There have also been instances when patients did not feel support and aid from the family, but rather distancing; they also mentioned cases in which patients with cancer have been abandoned by their partner after receiving the diagnosis or after mastectomy.

Social relationships beyond the family tend instead to deteriorate, both despite of marginalization and because patients are distancing themselves from relatives/friends. Initially, patients choose to withdraw from social life, determined either by the

poor physical and mental condition, or the need to hide the diagnosis, sometimes even because of the shame associated with the disease. Meanwhile, in many cases friends/relatives avoid the interaction with patients for various reasons: they do not know how to interact with them or are afraid that the disease is transmissible, which indicates a very poor level of health education.

Dealing with the disease has also brought the difficulty of performing the tasks at work. Overall, patients received emotional support (even financial) and understanding from colleagues and employers, but there are also situations when patients were suggested to give up their job or retire. For most patients, the possibility to work even during chemotherapy represents a sign of normality, that the disease has not defeated them. Thus, the understanding and support of the colleagues and employers means a chance for patients to feel more powerful, with control over their own lives.

The strongest impact in financial terms was in the period of diagnosis and surgical interventions. Subsequently, the costs have decreased, being reduced in most cases to “auxiliary” costs. To cover the costs that cancer diagnosis and treatment entail, patients were forced to make financial sacrifices or to request financial help from the people close to them. Some patients received financial support from work colleagues and the company they work for.

There were instances when the doctors did not inform them about the possibility of compensation/gratuity for the investigations, or waiting times were too high, so they paid for the investigations to receive the results quicker. Other indirect expenses are represented by trips to the hospital, food supplements/therapies to counteract the side effects of the cancer treatments, adopting a healthy diet or “gifts” offered to doctors.

6.2.2 Circuit of Patients through the Medical System

Although they are valued now, retroactively, prevention and early diagnosis actions are missing from the stories of the patients, as they visited the doctor generally after the onset of symptoms. Once they become aware of these, patients begin to gather information from family members, coworkers or acquaintances with medical training, before going to the doctor.

The main medical links involved in the circuit of patients with breast/cervical cancer are the gynecologist doctor, oncologist/surgeon oncologist and radiologist. In most cases, patients carry out repeated visits to these medical specialist areas,

which means that from the initial visit until the diagnosis and initiation of therapy there are delays of several months. The long waiting time to benefit from the gratuity or the compensation of investigations is also important. These mandatory stages are complemented by the patients' need for a second opinion, both in terms of diagnosis, and in connection with the need for a surgical intervention; in more special or severe cases, the limited access to specialist physicians with good reputation (who are very busy) also plays a part.

The confirmation of the suspicion of cancer and the establishment of the certain diagnosis is a destabilizing moment, because the disease involves major risks, for which, however, they do not receive sufficient information from doctors (about the disease, steps to take, side effects of treatment). At the time of the diagnosis, the patient and the dependent feel the need both of emotional support and informational support. However, the medical personnel does not cover any of these needs as expected.

Many times, the communication of the diagnosis is made with emotional detachment or in a negative manner, causing alarm, the focus being on the need to start therapy fast, and not on explaining the next steps. Doctors are reluctant to give a prognosis for survival, so patients and dependents seeking information as complete as possible on their own, from friends, relatives who have gone through a similar experience, online forums and people they know who are working in the medical field.

Questions of patients and dependents in the very moment of cancer diagnosis focus on:

- Causes of cancer development;
- Prognosis;
- Most effective therapies/therapeutic approaches;
- Role of chemotherapy and radiotherapy, before surgery.

Mastectomy and hysterectomy affect patients very strongly. If pre-surgery, mastectomy is accepted upon the recommendation of the surgeon, post-surgery it deeply affects the self-image of a woman, and sometimes how she is seen by the partner; even if she receives support from the family/partner, mastectomy brings fear of stigmatization and major changes in lifestyle, the couple dynamics and social relations in general. Hysterectomy represents, like mastectomy, a "chipping" of womanhood, even if its effects are not immediately visible. Thus, the initial surgical recommendation is rejected, and it is subsequently accepted at the insistence of the oncologist and the family.

Despite the major psychological impact, the recommendation of these interventions is presented on the run and without “delicacy”. Patients are informed about the need of operation without having too much time available to assess the advantages and disadvantages or to understand what to expect after that.

Patients would like to be informed about:

- Possibility of breast reconstruction/CNAS compensation program for prosthetics;
- Intra-operative situation, when the surgeon takes the decision of mastectomy;
- Duration of post-surgery recovery;
- Causes of recurrence.

Patients declared they had learned about mastectomy and the possibility of breast reconstruction from colleagues in the hospital; about the post-surgery physical recovery they have also informed themselves from the leaflets available in the oncology ward, in some hospitals in Bucharest.

Chemotherapy represents in turn a trauma for all patients. Hair loss is the most striking and lasting side effect of chemotherapy: it is traumatizing, it increases the aggression associated to chemotherapy and the fear of stigmatization.

Digestive symptoms (nausea, vomiting), fatigue or dizziness are present in most patients, but were felt at different intensities (some patients have gone through them with ease, while others were forced to give up work life).

In some cases the experience of chemotherapy treatment is demoralizing also due to the existing conditions in state hospitals: very long waiting times for hospital admission or procedures (in most cases standing, in a hallway), poor hygiene or administration conditions.

Patients would have liked:

- To be provided with a minimum comfort until the administration of the cytotoxic therapy (e.g. more waiting chairs/benches, not to stand for endless hours);
- More information about possible side effects and ways to overcome them;
- More information about the treatment plan (schedule of administration - how many days/how many treatments).

Patients have also completed their information from medical nurses who administered their chemotherapy, from ward colleagues, but also from the Internet; treating physicians were consulted when side effects were severe.

Access to radiotherapy at the right time is difficult. Radiotherapy treatments are effective, and side effects are more easily tolerated than in chemotherapy. The main drawback of radiotherapy is linked to the long waiting time for a free place to become available, at least three months. The issue of access to radiotherapy is maintained both in state hospitals, and private clinics which have concluded a contract with CNAS; additionally, unpleasant situations arise when patient appointments are not respected, because the demand is too big, so the therapeutic approach is delayed and the condition of the patients gets worse.

Patients and dependents would have liked that in radiotherapy emergencies are prioritized, when appointments are not respected. Dependents are forced to resort to a chain of acquaintances/friends until they find a doctor to facilitate access to radiotherapy.

Patient monitoring is mainly done by the oncologist and takes place every 3-6 months; to monitor cervical cancer therapy, the oncologist also communicates closely with the gynecologist. Some patients opt for private clinics due to more performing equipment, hygiene and more polite staff, while others choose state hospitals for experienced doctors.

6.2.3 Unmet Needs; Future Directions

The degree of satisfaction with the relationship with healthcare professionals is different. In general, the fact that doctors are over-loaded is limiting the information communicated to the patient to a “mechanical” discussion, which is usually one-sided and without offering the moral support the patient is looking for.

The experience of patients with healthcare professionals is assessed depending on the time allocated and the willingness to provide full information, as well as the attitude towards the emotional state of the patient. The ideal situation is the one in which: the information was complete and customized; the doctor got involved continuously in informing the patients and has managed the side effects of chemotherapy; in turn nurses inform and even supplement the information provided by the physician; the attitude of the medical staff is empathetic, patient and encouraging. Unfortunately, this situation is not very often met in reality.

There are many aspects which could simplify the experience for patients:

- More information about: necessary investigations, the level of gratuity, responsible medical specialist areas, surgical intervention, number and frequency of chemotherapy cycles, etc.
- Better/decent conditions in state hospitals and clinics (waiting areas with enough chairs, hygiene);
- Psychological support specialized in oncology, support groups where patients can share their experience with other patients, who are able to understand the drama they are going through;
- Transparency and professionalism from doctors and nurses;
- More attention and correct information from friends/relatives.

In order to better inform the patients and dependents and for a better understanding and integration of information, patients have suggested a series of educational materials, which should be available in health units, as well as online.

In order to improve screening programmes and patient experience post-diagnosis, the following actions may be considered:

- Involving more doctors (especially GPs) in the screening programmes so that the largest possible number of women are informed and enrolled in national screening programmes (as well as in the sub-programme for breast reconstruction for patients with mastectomy);
- Establishing centers specialized in cancer diagnosis and treatment (in which the entire set of investigations is carried out), to avoid late diagnosis and to streamline the investigation process (and hence the access to therapy), higher compensation of specific investigations;
- Facilitating the access to psychological support for both patients and dependents (individual or group therapy);
- Conducting awareness campaigns on the rights that cancer patients can benefit from (reduced hours at work, number of medical leave days to which they are entitled, the conditions whereby they may ask for retirement, etc.)
- Using credible ambassadors in communication (public figures active within the area of medical prevention or patients who have won the battle with cancer and can share their own experience) and organizing events.

CONCLUSIONS

The effort to “diagnose” the situation in Romania regarding the three types of female cancers - breast, ovarian and cervical - revealed multiple problems, each requiring a specific set of solutions. There are, on the one hand, insufficient funding problems, already well-known and widely discussed on the public scene. For the financial optimization of the medical system, however, a broader vision would be needed, which goes beyond the direct, immediate, short-term cost-benefit ratio. The correct implementation of a screening programme for breast cancer, for example, is a major cost center, requiring additional budget allocations in the short-term.

On medium and long-term, however, it is likely we shall witness a reduction in the costs that the health system would bear with these three forms of cancers as a result of early diagnosis, when the therapeutic methods available allow not only to extend the life of the patients, but also their social and economic reintegration, with beneficial effects for the economy. Similarly, the use of modern therapies may involve significant immediate costs, but at the same time, these can allow increased survival rates, the enhancement of the quality of life and the return of patients to work - an aimed-for objective for most of them, as we have seen.

Another very important category of issues is related to logistics and the organization of the health system itself. The circuit that patients should follow is long, cumbersome and ineffective, which raises extremely difficult barriers to overcome in order to achieve an early diagnosis. Faced with the prospect of several trips to various medical institutions - endless hours of waiting, days in which they are taken out from the productive activity and the related costs - many women prefer to quit, even more so as, in their view, “they are feeling well”. Physicians, in turn, suffocated by this cumbersome process, do not encourage patients to carry out regular investigations, or do not do it in a sufficiently compelling way, in the absence of symptomatology or belonging to an obvious risk category.

The lack of clear procedures for interdisciplinary collaboration, the lack of reporting and real-time consultation systems of the files of patients, the lack of a national register of patients are aspects that uselessly hinder an overloaded system. Solutions could however be at hand: the establishment of cooperation protocols based on internationally accepted variants, namely the creation of an electronic database, accessible to all physicians dealing with a patient, as it was being foreseen when the electronic cards were issued.

Finally, perhaps the category that is most difficult to define is the one of communication problems in the widest sense of the word. We include here the lack of health education programmes in schools - with serious and long-term repercussions, as we have seen.

This category also includes the difficult communication between physicians and patients, due both to the lack of education of the patients (that physicians point out), and the lack of training of physicians in managing patients, particularly in difficult situations, such as the news of a cancer diagnosis. According to the statements of the interviewed physicians, the faculties of medicine in Romania do not include in the curriculum courses for communication or psychology of the patient. In these circumstances, doctors must find their own solutions to address difficult discussion topics, with variable success rates, such as it was revealed in the interviews with the patients.

Communication between doctors with different specializations is hindered by the lack of support systems, as we have seen, most often being the duty of the patient to transmit information from one doctor to another.

More difficult to explain is the absence of official communication actions with the patients or the general public, regarding standard prevention and early diagnosis programmes or procedures for these forms of cancers. Why don't Romanian women find out about the existence of screening programmes, why don't patients receive a guide with the steps they need to take from diagnosis to the end of the treatment, why aren't their legal options explained to them?

These are questions that are very difficult to answer. This type of actions can be achieved through public-private partnerships, and the effects, apart from limiting the stress levels of patients, would also be felt by the system, by streamlining their journey through the medical system and the release of healthcare professionals from some administrative tasks.

This variety of problems requires a variety of solutions, that can come from the authorities, from healthcare professionals or from the civil society, having different time and investment horizons. Unfortunately, there is no "panacea", however, luckily, the absence of a unique solution means that many issues can be solved gradually, specifically, with immediate positive effects for the lives of Romanian women.

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