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Special Report

Changing the Future of Chilean Women

Challenges in Early Diagnosis of Breast Cancer and Opportunities to Improve

Contents

Executive Summary

Cancer comprises more than 100 diseases in which abnormal cells divide uncontrollably and destroy body tissue. Cancer is a global and growing problem that in 2018 attacked 18.1 million new people and killed 9.6 million. [1]

Although medicine has made good progress in combating the disease, mainly through scientific discoveries and development of new and more effective therapies, the number of people affected by cancer is expected to grow. According to recent projections, the incidence and mortality of cancer will increase by 63% and 71%, respectively, reaching 29.5 million new patients and 16.4 million deaths each year by 2040. [4]

A few types of cancer make up most of the cases and will continue to be the main causes of cancer mortality in the future.

Breast cancer is one, leading in the number of new cases and deaths among women worldwide. In 2018, almost 2.1 million women were diagnosed with breast cancer, and more than 630,000 female patients died from it. [4]

In Chile, the reality is no different. Despite a lack of reliable data, our analysis suggests that around 5,900 women each year receive a breast cancer diagnosis. Moreover, breast cancer is the leading cause of death among Chilean female cancer patients. It is responsible for more than 1,500 lives lost each year, a figure that is expected to grow to approximately 2,800 in 20 years.

However, the real statistics might be even worse, as the real epidemiological status of breast cancer in Chile is unknown, since the country lacks a national cancer registry, and the published statistics do not include women who have cancer but have not received a formal diagnosis. [1] [19]

With the intention of providing additional perspective on how to improve breast cancer care in Chile, we developed a comprehensive study with quantitative and qualitative phases, including in-field research, that yielded a holistic view of the problem and how to better address it.

First, we applied a proprietary methodology to gain an unbiased and realistic view of the problem. This methodology takes incidence rates in developed countries, whose healthcare systems tend to be more efficient, and adjusts them based on the age and ethnic profile of the Chilean population.

The analysis suggests that in Chile around 11,200 women develop breast cancer annually, leading us to believe that almost 5,300 women are either sub-notified or improperly diagnosed.

The issue is not evenly distributed across the Chilean population. Approximately 98% of the 5,300 undiagnosed patients are covered by FONASA (Fondo Nacional de Salud), and even within FONASA there are substantial differences across regions.

In general, the southern regions have performed better than the rest of the country, even better than Santiago, which contains the majority of human and physical infrastructure in the country.

To understand the factors driving differences in performance across the country, we interviewed 80 professionals, including *matronas* (midwives), breast surgeons, radiologists, pathologists, and employees of Servícios de Salud and Ministerio de Salud (Minsal), as well as representatives from third-party institutions, such as private companies and patient associations, across Santiago, Los Ríos, Atacama and O'Higgins.

During the interviews, we discussed the current standard of care and the major barriers faced by Chilean women at each step of their cancer journey. The interview campaign indicated that the major challenges relate to six main matters.

Lack of awareness and general prevention culture	The general lack of prevention culture in the Chilean population inhibits early diagnosis, thus reducing chances of a cure. Additionally, current efforts to increase breast cancer awareness are limited to October, reducing the reach and impact of these initiatives.
Lack of primary care infrastructure	Although the amount of infrastructure varies greatly across the country, there seems to be a lack of primary care professionals and settings in many regions, translating into long waiting lines and unavailability of certain services, ultimately leading patients to seek help only when more severe symptoms appear.
Limited professional experience with breast cancer	Many primary care professionals have limited experience with breast cancer patients and protocols, which limits their capacity to properly assist Chilean women. The lack of experience relates to limited exposure to breast cancer during medical training, and a further lack of training in daily work.
Limited access to high-quality screening and confirmatory exams	Access to high-quality screening mammography and confirmatory imaging exams is restricted by limited infrastructure in the public network, limited budget for exam outsourcing, and low quality of some private providers, the latter resulting in a high number of inconclusive cases.
Limited incentives and public policies for risk assessment and screening	There are no public policies to incentivize patients to seek mammography and no professionals to actively recruit patients, as is done with other diseases, such as cervical cancer. Moreover, current policies do not cover novel exams (e.g., BRCA testing) and are poorly communicated to society. [20]
Low levels of patient support and system coordination	Patients lack adequate support to navigate the multilevel healthcare system in Chile, as there are no stakeholders dedicated to providing legal and psychological assistance. Additionally, management of public resources is suboptimal, leading to unequal availability of services across and within regions.

Based on these problems, we believe that a broad response including awareness generation, higher investment in primary care and screening, promotion of early detection, and patient support is badly needed to save lives.

1 Prevention culture and awareness	Conduct continuous awareness and prevention campaigns with local efforts that respect regional peculiarities and address specific gaps in each location.
2 Primary care enhancement	It is pivotal to better equip primary care professionals to properly assess, refer and support potential patients. We recommend creating a closer relationship between the primary and secondary care levels to enable knowledge sharing; enhancing the undergraduate curriculum, with more hours of theoretical and practical activities related to breast cancer; and revising and revamping the *cápsulas educacionales*.
3 Investment in quality screening	To increase the rate of early diagnosis, there should be greater investment in high-quality mammography. For that, it is necessary to increase availability of exams by acquiring more equipment, increasing budget for outsourced exams, optimizing related human resources, and creating quality standards for both public and private settings.
4 Patient support program	Patients demand better support, from the moment they have a suspicion of breast cancer through to treatment, to help them access services faster and stick with the process. Government, private companies and the third sector have to combine efforts to embrace Chilean women from the initial moments of their journey to their cure.

The time to act is now, and it is a common responsibility of the government, private companies, the third sector and society to help reshape the future of Chilean women.

Cancer — A global and growing problem

The International Agency for Research on Cancer (IARC) expects 20% of men and 17% of women in the world to develop cancer at some point in their lifetime. Moreover, IARC estimates that in 2018 alone, 18.1 million people were diagnosed with some type of cancer, and 9.6 million died of cancer.

In fact, according to the American Cancer Society, cancer causes 16% of all deaths around the globe, ranking as the second most fatal disease worldwide.

Currently, both incidence and mortality are concentrated in a few types of cancer. The most common types of cancer are lung, female breast, colorectal, prostate and stomach, which together represent almost half of new cases and cancer deaths in the world. [1]

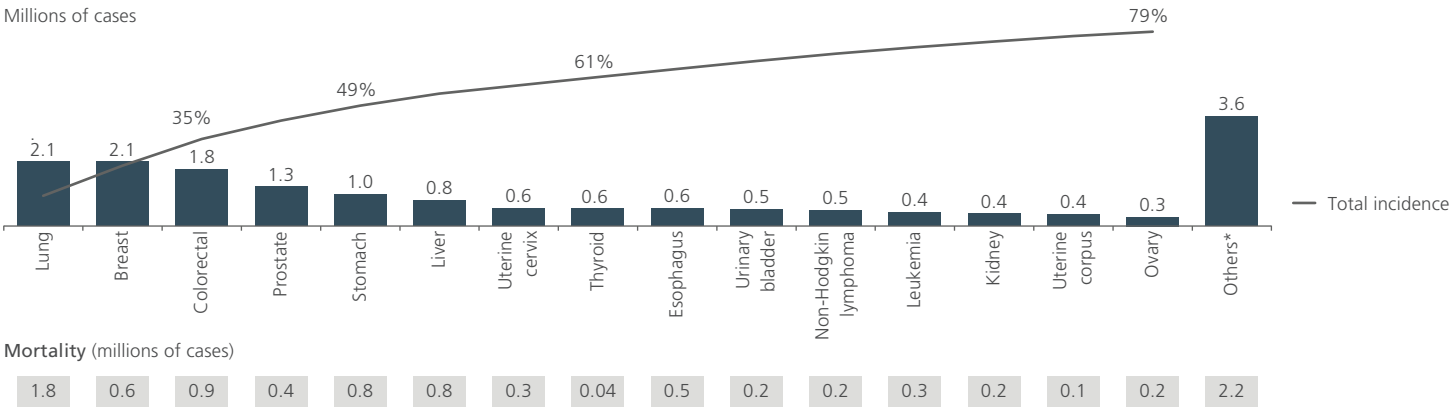
Much has been done worldwide to combat cancer. This progress was possible because of scientific discoveries and development of new and more effective drugs by academia and pharmaceutical companies, as well as more investment by governments in prevention and early detection. [5]

This collaborative effort improved survival rates for cancer patients. According to the Organisation for Economic Co-operation and Development (OECD), the survival rates for multiple types of cancer have improved in recent decades in member countries.

Despite this good progress, by 2040 the number of new cases of cancer each year is expected to grow to 29.5 million, and the annual number of deaths is expected to grow to 16.4 million, an increase of around 63% and 71%, respectively. [4]

Figure 1

Incidence by selected types of cancer (2018)

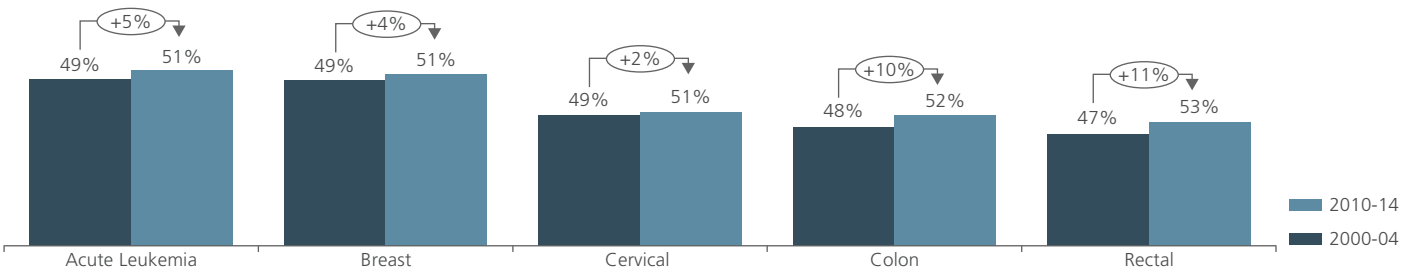


*Excluding non-melanoma skin cancers

Source: International Agency for Research on Cancer, American Cancer Society

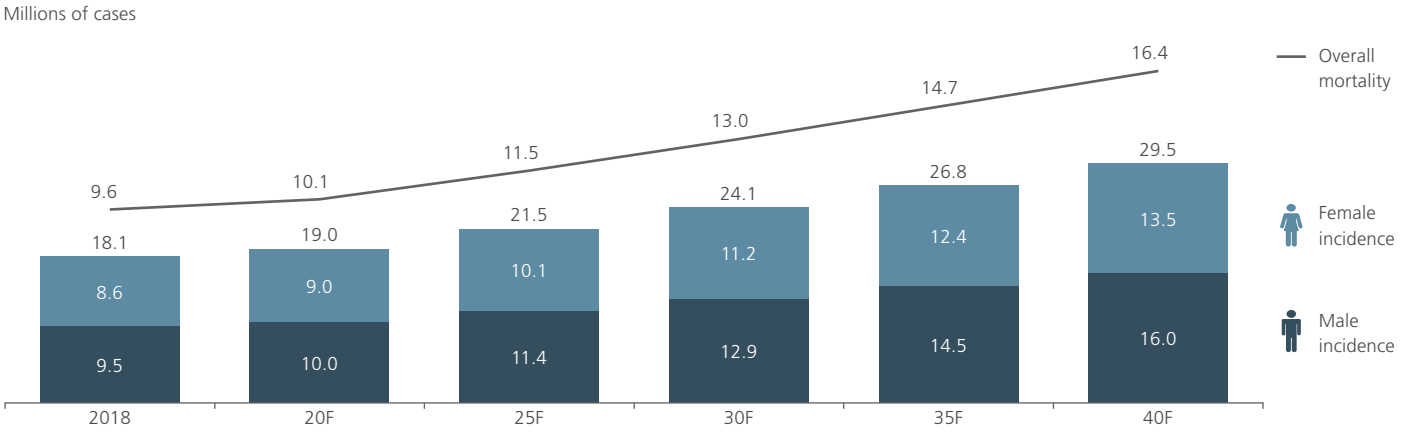
Figure 2

5-year patient survival rate in OECD member countries by selected types of cancer (2000-14)



Source: Organisation for Economic Co-operation and Development

Figure 3
Incidence by sex and overall mortality of all cancers (2018-40F)



Source: International Agency for Research on Cancer

The reasons behind such trends are complex, but key aspects include growth of risk factors, such as an aging population and unhealthy habits such as smoking. [3]

The incidence and mortality of cancer vary not only by site, but also by where the patient lives. The burden of cancer is more significant in low- and middle-income countries, where 70% of cancer deaths are concentrated. [2]

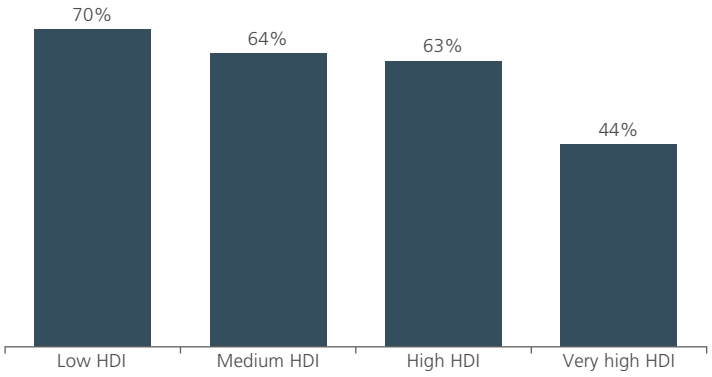
In addition to the lack of financial resources dedicated to cancer, low- and middle-income countries have suffered from low investment in the healthcare system as a whole, resulting in deficits in the training and availability of health professionals and poor physical infrastructure for healthcare. As a consequence, more people are impacted by and die of cancer because of late diagnosis; limited access to treatment and palliative care; and, most important, lack of formal diagnosis. [7]

According to the World Health Organization (WHO), in 2017 only 26% of low-income countries reported the existence of pathology services in the public healthcare system and less than 30% reported broad access to cancer treatment, compared to 90% availability in high-income countries.

Such limited access to early diagnosis and adequate treatment translates into high cancer mortality rates in low- and middle-income countries.

The inequalities evidence the urgency of adopting an immediate action plan to control the current and future impacts of cancer in these regions.

Figure 4
Mortality rate* of cancer by level of development (2018)



*Excluding non-melanoma skin cancers
Source: American Cancer Society

The many faces of breast cancer

Breast cancer is the leading type of cancer in terms of the number of new cases and deaths among women worldwide. In 2018, IARC estimates almost 2.1 million women were diagnosed with breast cancer and the disease was responsible for 630,000 deaths around the world. [4]

Breast cancer is the result of uncontrolled growth of invasive cells in the tissues of the breast. Normal breast cells become cancerous because of mutations in their DNA. [16]

There are two types of DNA mutations associated with breast cancer. The first and most common type is an acquired mutation that takes place during the woman's lifetime; the main causes of this are still unknown. The second type is caused by inherited genes, such as BRCA1 and BRCA2, and can be easily identified through genetic testing. [14]

Apart from an inherited mutation, many other risk factors increase the chances of developing breast cancer.

Age is the most important factor, followed by many others, including family history of breast cancer in a first-degree relative, dense breast tissues, natural exposure to estrogen because of early menstruation, lack of childbirth, late menopause, use of some hormone replacement therapies and alcohol ingestion. [15]

Although breast cancer is commonly referred to as a single disease, there are up to 21 distinct histological subtypes and at least four different molecular subtypes that differ in terms of risk factors, presentation, response to treatment and outcomes. In general terms, breast cancers can be combined into three groups based on place of origin in the organ and the presence of invasive cells. [16]

In situ cancers are the first stage of the disease, and are characterized by the absence of invasive cells in the nearby tissues. The most common *in situ* cancer is ductal carcinoma, which represents more than 80% of cases and develops when abnormal cells replace the normal epithelial cells that line the breast ducts. [13]

The second type, representing 13% of all *in situ* cancers, is lobular carcinoma *in situ*, characterized by growth and expansion of abnormal cells within some of the lobules of the breast, and which might be a precursor of invasive cancer. [16]

The third group of cancer is characterized by invasive cells (i.e., cells that have broken through the originating walls of the glands or ducts and grown into nearby breast tissue).

The process of breast cancer diagnosis usually begins with the patient or physician noticing a lump, nodule or abnormal mass in the breast through self- or clinical examination or mammography. [17]

Once there is a suspicion, the patient undergoes an ultrasound and a biopsy (a surgical procedure to remove part of the tissue or fluid from the breast). The samples are analyzed using biological markers to identify the presence of hormones (estrogen or progesterone), receptors (HR+ / HR-), and excess levels of human epidermal growth factor receptor 2 (HER2). This analysis confirms the presence of cancer and characterizes its subtype to help determine the right treatment. [17]

The burden of breast cancer in Chile

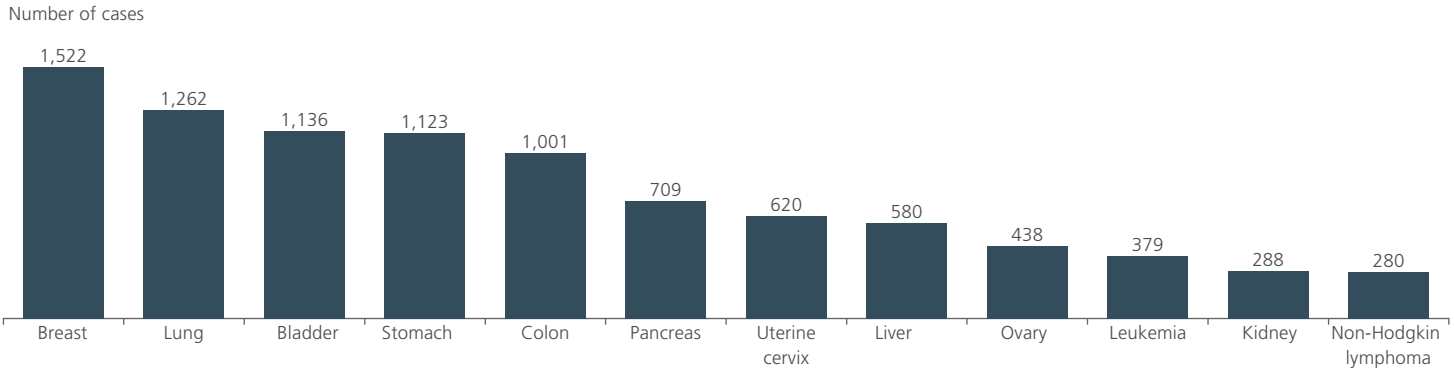
The number of annual diagnosed cases in Chile is unknown, because the country lacks a national patient registry and information from regional registries is outdated. However, triangulation of information from private and public sources, such as Minsal, Universidad de Chile and Globocan, indicates about 5,900 new cases of breast cancer per year in Chile.

As in other countries, in Chile breast cancer is also the leading cause of death among female cancer patients. According to Minsal, in 2015 about 1,500 women in Chile died of breast cancer; mortality for breast cancer has grown by 42% in the past 15 years, well above the 25% average for other cancers. [9]

When compared to that of other countries, Chile's breast cancer mortality rate suggests the country still lags behind other Latin American and more developed nations in terms of providing high-quality cancer care.

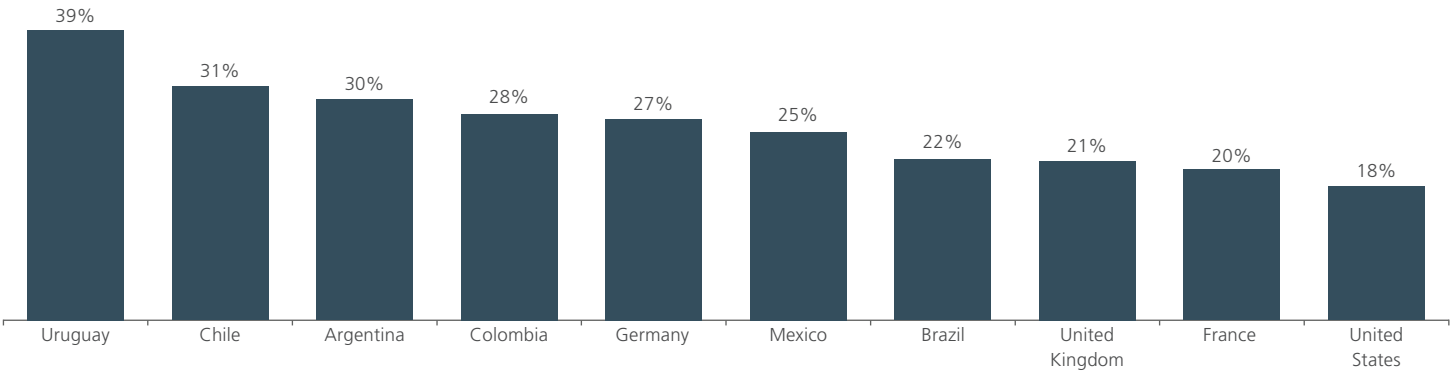
The burden of breast cancer is expected to increase in the future. WHO estimates that by 2040, the number of new cases of breast cancer in Chile will increase by 45%, to reach approximately 8,000 new patients per year. Additionally, cancer mortality is expected to have an even stronger growth of 67%, resulting in almost 2,800 deaths every year.

Figure 5
Female mortality by selected cancers, Chile (2015)



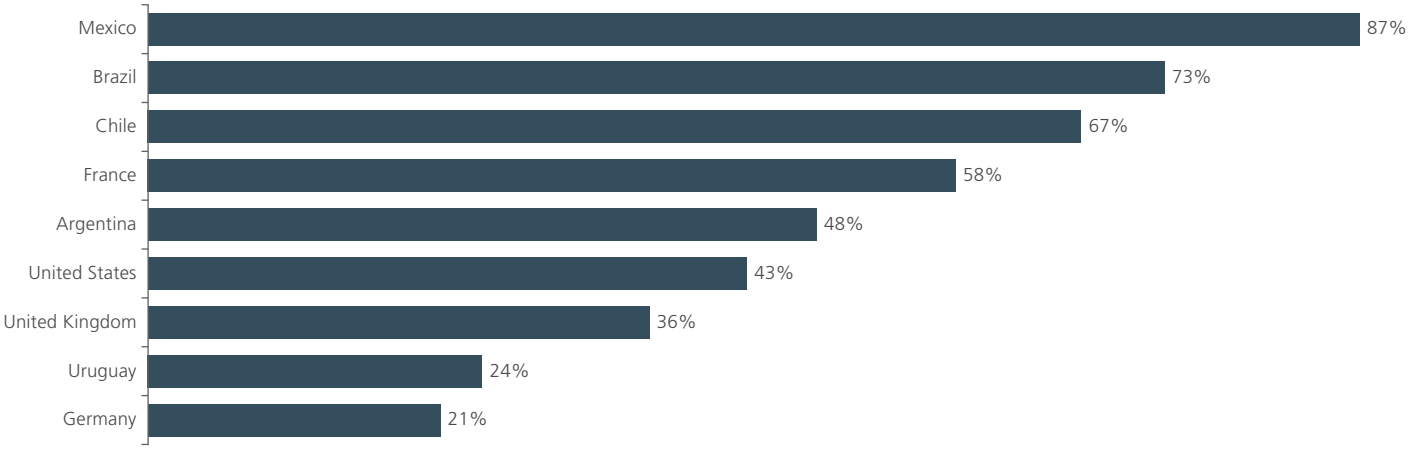
Source: Departamento de Estadísticas e Información de Salud (DEIS)

Figure 6
Mortality rate of breast cancer by selected countries (2018)



Source: International Agency for Research on Cancer

Figure 7
Mortality growth of breast cancer by selected countries (2018-40F)



Source: International Agency for Research on Cancer

Although the growth of cancer mortality is a reality in all countries, the expected increase in the number of deaths caused by breast cancer in Chile is considerably higher than that of other Latin American countries, such as Argentina and Uruguay, and more developed countries.

The Chilean government acknowledges the need to better diagnose and treat breast cancer and has taken substantial steps to improve access to care. The first step was to include, in 2005, breast cancer in the Garantías Explícitas en Salud (GES), with the goal of guaranteeing universal access to diagnosis, surgery, radiotherapy, initial pharmacological treatment and financial protection for all patients affected by breast cancer in Chile. [10]

Another important milestone was the establishment of the Ley Ricarte Soto (LRS), which guarantees additional therapies, including coverage of high-cost drugs. In the case of breast cancer, the LRS provides free trastuzumab to all women diagnosed with HER2+ — between 15% and 20% of the patients. [11] [12]

In addition to the current resources designated for GES and LRS, the Chilean government plans to further invest in combating breast cancer. The Ley Nacional de Cáncer, for example, is a regulation currently in the approval process that highlights, among other points, the need to adequately fund and regionalize cancer prevention and care in Chile.

The main output of this bill is the Plan Nacional de Cáncer, which has already been released and aims to reduce both cancer incidence and mortality through promotion of awareness, prevention, early diagnosis, treatment, palliative care and patient follow-up.

This paper's main objective is to further encourage discussion of breast cancer in Chile by providing additional perspectives on how to support patients, based on a holistic view of the barriers Chilean women face in accessing breast cancer diagnosis and treatment.

The problem of undiagnosed patients

As previously mentioned, Chile lacks a national registry of cancer patients. This limits a proper view of the epidemiological status of breast cancer.

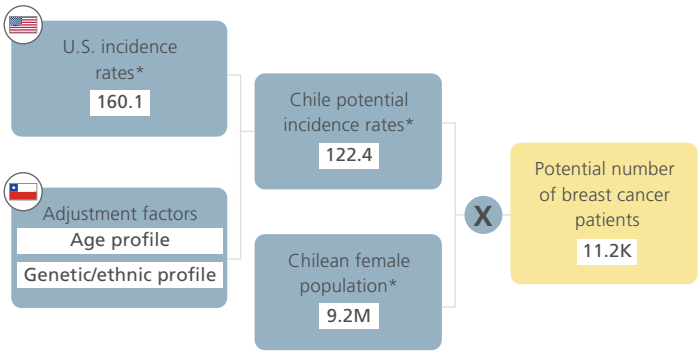
The Economist Intelligence Unit highlighted this problem in its study of cancer in Latin America, done in 2017, in which the group discovered that although Chile has multiple individual registries, these databases cover only a small part of the population. [19]

However, the development of a national registry of cancer patients is only the first step. Subsequently, in order to gain a clear understanding of the impact of breast cancer on Chilean women, it is essential to understand the existing system inefficiencies that hinder access to proper diagnosis.

Currently, the incidence of cancer is estimated based on an extrapolation of data available in Los Ríos, Antofagasta and Biobío, which together cover around 7% of the population.

Acknowledging that the data available is unreliable and outdated and considers only diagnosed cases, we have applied a proprietary methodology to gain an unbiased and realistic view of the prevalence of breast cancer. This methodology adjusts incidence rates in developed countries, whose healthcare systems tend to be more efficient, for the age and ethnic profile of the Chilean population, as depicted in Figure 8.

Figure 8
Study methodology



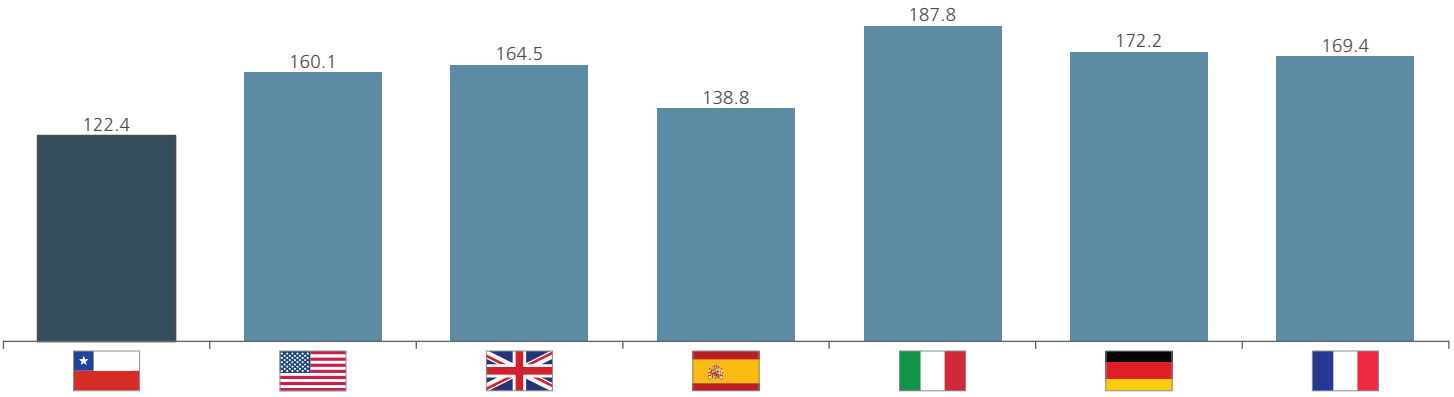
*Segmented by age group and by ethnicity
Source: SEER, DEIS, Minsal, Mayo Clinic, Universidad de Chile, Altura Management, L.E.K. Consulting

The analysis suggests that in Chile approximately 11,200 women develop breast cancer annually.

Although the methodology has limitations, especially regarding the incidence among indigenous populations, the estimated rate dovetails well with crude rates in more developed countries where patients do not face significant barriers to definitive diagnosis and appropriate treatment.

Figure 9
Crude potential incidence rate by selected countries (2019)

New cases per 100,000 women



Source: Globocan, SEER, L.E.K. analysis

Comparing the estimated number of new cases per year (11,200) with the current number of patients diagnosed per year (about 5,900) suggests a potential gap of 5,300 women each year who are either sub-notified or improperly diagnosed.

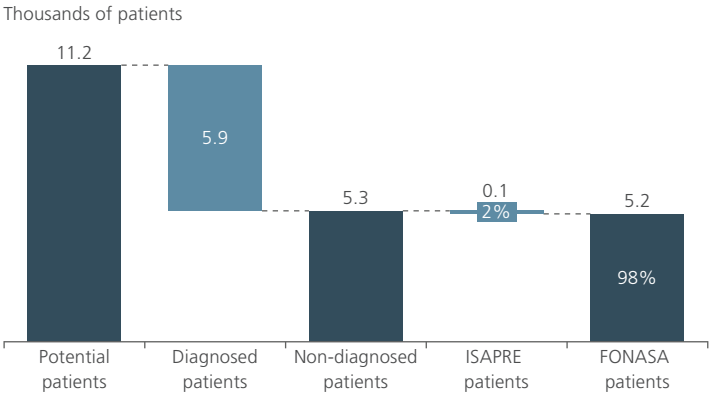
Yet the issue is not homogenous among the Chilean population. Unsurprisingly, the vast majority of the 5,300 undiagnosed patients — approximately 98% — are covered by FONASA.

However, even within FONASA there are substantial differences, especially across regions. In general, the southern regions, apart from Los Lagos, do a better job than the rest of the country at getting women with breast cancer diagnosed. Los Ríos leads the ranking and is the only region where mammography screening rates are higher than the rates of receiving Pap smears.

The ranking contradicts our initial hypothesis that central regions would outperform the rest of the country. Santiago's performance,

Figure 10

Breakdown of potential breast cancer patients, Chile (2019)

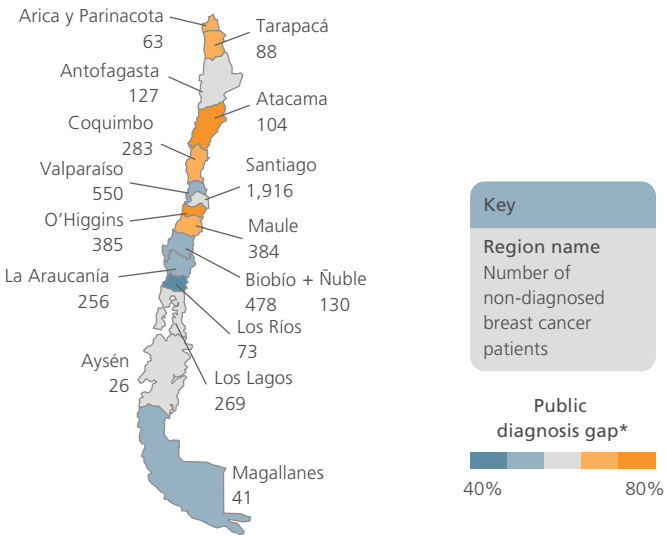


Source: INE, SEER, FONASA, World Atlas, Latinobarómetro report, Revista Médica de Chile 2014 (Fuentes et al.), Globocan, Altura Management, Universidad de Chile, Minsal, Economía y Negócios newsletter, L.E.K. Consulting

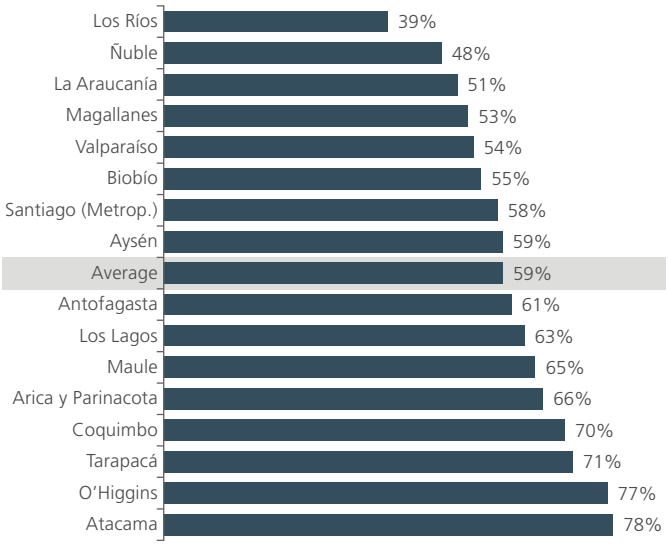
Figure 11

The gap in the public system

Non-diagnosed patients of FONASA by region
(2019)
Number of patients



Non-diagnosed patients gap* by region
(2019)
Percentage of potential patients

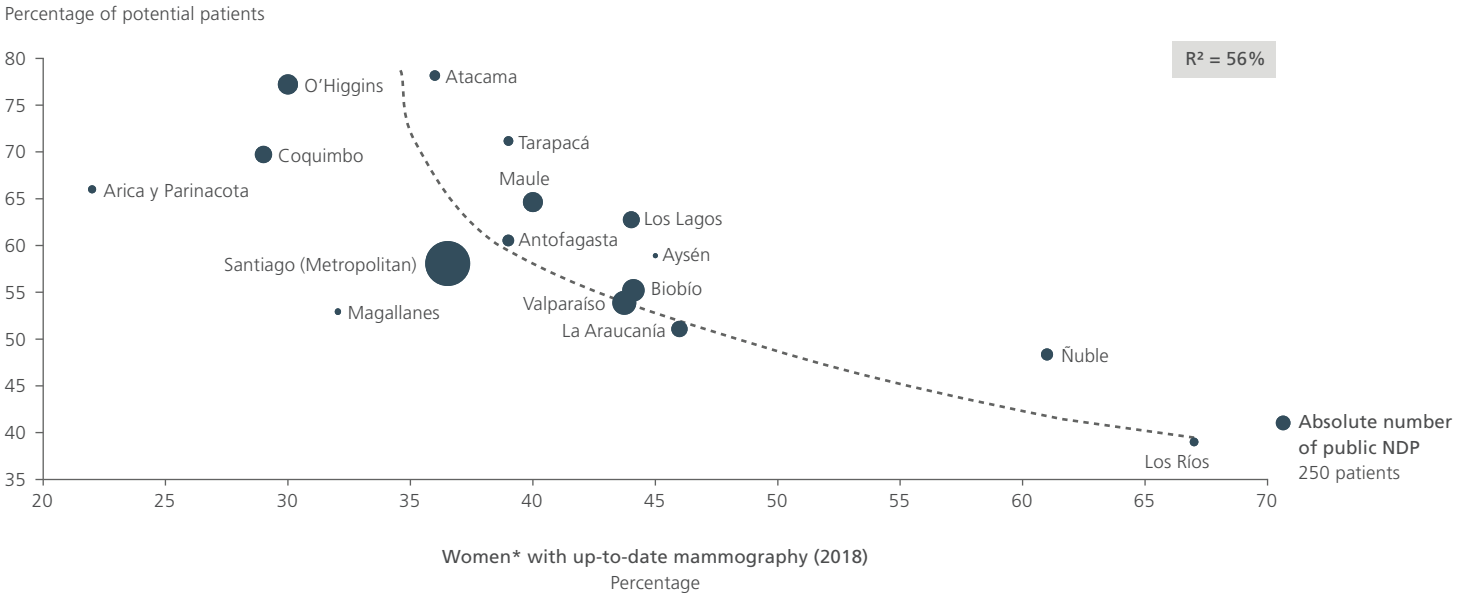


*Number of non-diagnosed patients divided by total number of potential patients

Source: INE, SEER, FONASA, World Atlas; Latinobarómetro report; Revista Médica de Chile 2014 (Fuentes et al.), Globocan, Altura Management, Universidad de Chile, Minsal, Economía y Negócios newsletter, L.E.K. Consulting

Figure 12

Public diagnosis gap by region vs. mammography screening rate (2019)



*Women ages 50 to 69 in the public health system
Source: Minsal, L.E.K. analysis

in particular, was surprising as the city holds the majority of the country's human capital and physical infrastructure.

On the other hand, the performance of the northern regions was in line with our initial expectations. The territories up north, with the exception of Antofagasta, are the most critical locations in terms of undiagnosed patients, followed by O'Higgins and Coquimbo in the central area, which also have poor diagnostic performance in both absolute and percentage terms.

To explain these inequalities, we performed a series of analyses considering multiple factors, with the conclusion being that the main factor determining whether breast cancer cases are identified is the mammography screening rate. Not surprisingly, it is higher in the three regions with the best diagnostic performance in the country.

However, we acknowledge that the screening rate is a complex variable, since it depends not only on imaging infrastructure, but also on the awareness and educational levels of the population and on access to and quality of primary care services.

To understand the factors driving the performance of the distinct regions, we conducted an extensive interview campaign in four regions that were selected based on their diagnosis performance. The first region was Los Ríos because it had the best performance in the country. Subsequently we selected Santiago, responsible for the largest number of non-diagnosed patients in absolute terms. The remaining two regions were Atacama and Coquimbo because they have the poorest diagnosis rates in the country.

The existing barriers

The large number of undiagnosed patients relates to access barriers that inhibit women from receiving a proper diagnosis and treatment. To better understand these barriers and the causes of the regional differences, we interviewed 80 key stakeholders among matronas, oncologists, surgeons, radiologists, pathologists, and representatives from Servícios de Salud, Minsal, private companies, and nonprofit organizations across Santiago, Los Ríos, Atacama and O'Higgins.

In these discussions, we explored the structure of the public healthcare system, the steps in the patient journey and the problems patients face in this journey.

The first step of the journey is the risk assessment, in which a matrona or a primary care physician consults with and assesses the patient to determine whether she belongs to a risk group and needs further evaluation.

If the patient belongs to the risk group, she is referred for a mammogram, which in about 75% of cases is performed in a private radiology center, as the public infrastructure is not sufficient to serve all women.

If the results of the exam suggest a potential malignant tumor (BI-RADS 4 and 5), the patient undergoes a biopsy of the presumable tumor; samples are then sent to pathology services for definitive diagnosis. The process involves basic histological analysis, immunohistochemistry and FISH (fluorescence *in situ* hybridization) tests, and typically happens in more than one center, as few pathology services in the country have the infrastructure to perform FISH exams.

Treatment is the final step of the journey and, depending on the stage of the cancer, may involve surgical intervention, pharmacological treatment, radiotherapy and/or palliative care.

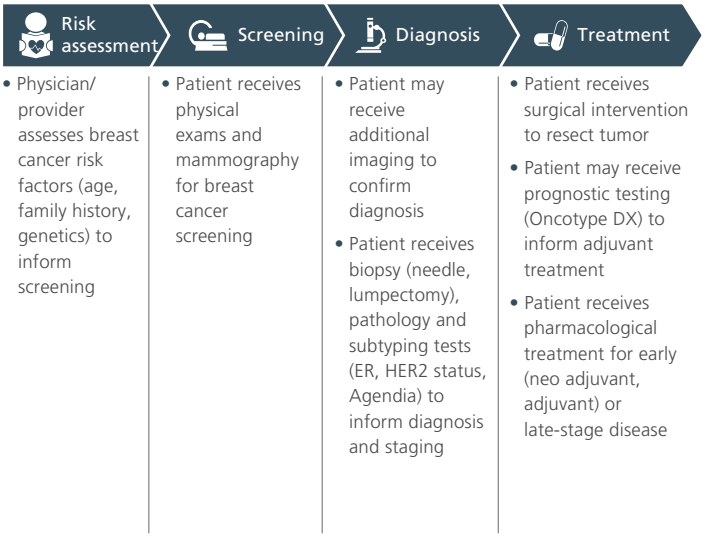
Table 1
Completed interviews by location and by position of interviewees

		Santiago	Los Ríos	O'Higgins	Atacama	Total
Matronas	APS	9	3	3	3	18
	UPM	4	2	1	1	8
Surgeon		7	2	2	2	13
Pathologist		2	1	-	1	4
Oncologist		2	1	1	1	5
Radiologist		1	1	1	3	6
Servicio de Salud administrator		2	1	-	1	4
Private sector employee		12	-	-	-	12
Data experts		2	-	-	-	2
Administrative key opinion leader (KOL)		4	-	-	-	4
Foundation representative		3	-	1	-	4
Total		48	11	9	12	80

Source: L.E.K. analysis

An overview of the patient journey is depicted in Figure 13 below.

Figure 13
Macro steps of the breast cancer patient journey



During the interviews, we identified 45 barriers hampering women's access to proper diagnosis and treatment. These barriers can be organized into four groups based on the underlying cause, as follows:

- **Patient behavior:** Barriers related to awareness of the disease, lack of prevention culture and attitude toward copay needs.
- **Professional behavior:** Barriers related to education of matronas and physicians, including guidelines and conduct during the consultation.
- **Infrastructure:** Barriers associated with suboptimal human resources and physical infrastructure.
- **Access policies:** Barriers related to coverage policies and requirements of Minsal and FONASA.

The vast majority of barriers are concentrated in the initial steps of the patient journey, suggesting, once more, that low access to mammography — because of the low rate of referral and suboptimal infrastructure levels — is the main problem Chilean women face. The number of barriers by type and step of the patient journey is depicted in the table below.

Table 2
Barriers by type and step of the patient journey

	Risk assessment	Screening	Diagnosis	Treatment	Patient navigation
Patient behavior	3 barriers	-	-	2 barriers	-
Professional behavior	8 barriers	3 barriers	4 barriers	1 barrier	1 barrier
Infrastructure	2 barriers	6 barriers	5 barriers	3 barriers	1 barrier
Access policies and incentives	3 barriers	1 barrier	-	-	2 barriers
Total = 45	16 barriers	10 barriers	9 barriers	6 barriers	4 barriers

Source: L.E.K. analysis of the ideation outputs

Table 3
Group of cities by level of primary and secondary care infrastructure

Groups of cities		# comunas	% of women population	Potential breast cancer patients	Primary care infrastructure	Secondary and tertiary care infrastructure
Developed cities	Santiago	52	~41%	4,565	Established	Established (*some developed cities may also lack infrastructure*)
	Other	39	~15%	1,813		
Developing cities		63	~27%	2,932	Established	Emerging
Rural and remote areas		192	~17%	1,902	Emerging/lacking	Lacking

Source: DEIS, Minsal, L.E.K. Consulting

Although some barriers are consistent across the country, others vary by region. Our analysis of the regional barriers suggests that there exist three major archetypes of cities in Chile in terms of healthcare infrastructure and access problems, as shown in Table 3.

The first archetype represents the developed cities in the country, such as Santiago and Valdivia, which have more infrastructure across all stages of care. Apart from the national barriers, these locations have only a few challenges, with moderate impact on the patient journey.

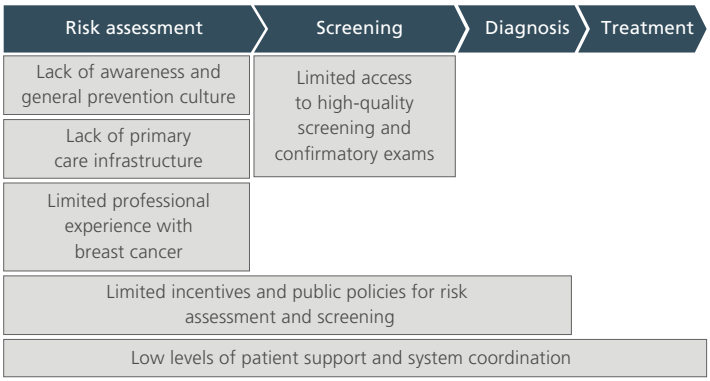
The second group (developing cities), on the other hand, has an established primary care system but underdeveloped secondary and tertiary care levels. This group includes cities such as Arica, Antofagasta and Rancagua, which are affected by almost all the barriers identified, as women living in the *comunas* (smallest administrative unit in Chile) of this second archetype also experience barriers faced by women in developed cities.

At the secondary and tertiary care levels, the major challenges include limited physical infrastructure such as equipment to perform stereotactic biopsies, surgical beds and staging equipment, and lack of specialists such as pathologists, oncologists and surgeons.

The third group, rural and remote areas, are characterized by limited access to primary care and nonexistent secondary and tertiary care. Patients living in cities of this group, which includes locations such as San Antonio, San Fernando and Villarrica, face three major additional barriers: limited access to an APS (primary care), limited access to experienced professionals, and lack of financial support for transportation.

Nevertheless, 12 barriers are common to the three city archetypes. We clustered these national issues into six groups according to their nature. Whereas three groups are specific to the risk assessment step, two also impact women at the screening step and

Figure 14
Group of major barriers



Source: L.E.K. interviews and analysis

one spans the full patient journey. These six groups are shown in Figure 14 and will be further detailed in the next sections.

1. Lack of awareness and general prevention culture

The first national barrier to early detection of breast cancer is the general lack of prevention culture among the Chilean population.

This problem — which is not exclusive to breast cancer — leads patients to wait for more severe symptoms before they seek help, inhibiting early diagnosis and reducing the chance of a cure.

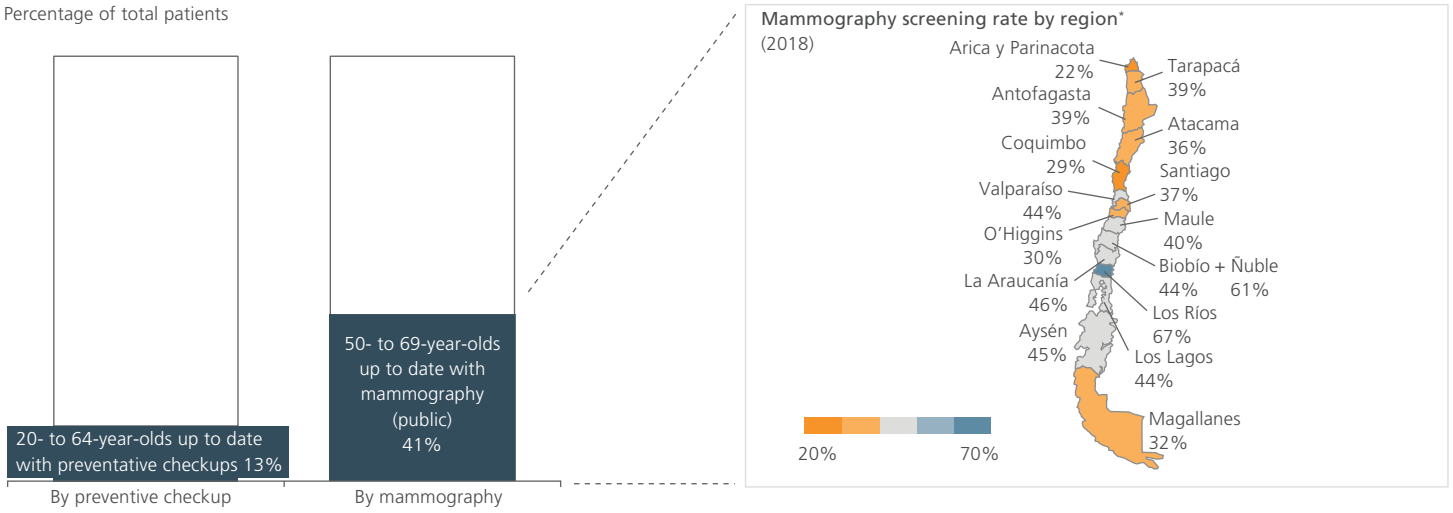
> *"… The main barriers are social. Patients do not do the preventive exams; they will only see a doctor if something is wrong …"*
>
> *Former executive, Minsal*

Moreover, in Chile, campaigns to increase awareness of breast cancer are concentrated in specific periods of the year, especially Pink October.

Both the content and the frequency of these campaigns seem inadequate, given the lack of awareness and knowledge of the benefits of early diagnosis. These campaigns also lack information about existing policies and programs that cover Chilean women.

The combination of these factors translates into extremely low rates of general checkups and mammography screening, as shown in Figure 15.

Figure 15
Chilean women checkup and mammography adherence (2018)



Notes: *Percentage of women ages 50 to 69 with up-to-date mammograms
Source: Minsal, "Plans to obtain a mammogram among Chilean women: the roles of recommendations and self-efficacy," L.E.K. interviews and analysis

2. Lack of primary care infrastructure

In general, Chile has a relatively low number of primary care professionals, especially compared to more developed countries, which hampers the access of those without private insurance to basic medical services.

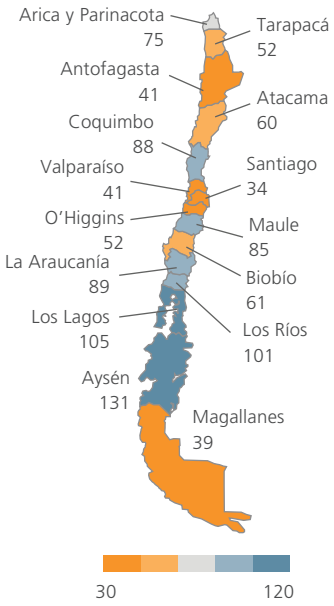
The extent of the problem for women, however, varies by region, as primary care infrastructure is very heterogeneous across the country, yielding huge inequalities in access.

Patients have to wait long periods for a consultation; consultations in more distressed areas tend to be just a few minutes long, without a proper evaluation of the patient; and in some settings, basic services are not available, as indicated by healthcare professionals in all regions we visited.

"... There is a lack of healthcare professionals, especially matronas, in primary care ..."
Administration employee, Servicios de Salud Metropolitano

Figure 16
Number of matronas per capita* (2016)

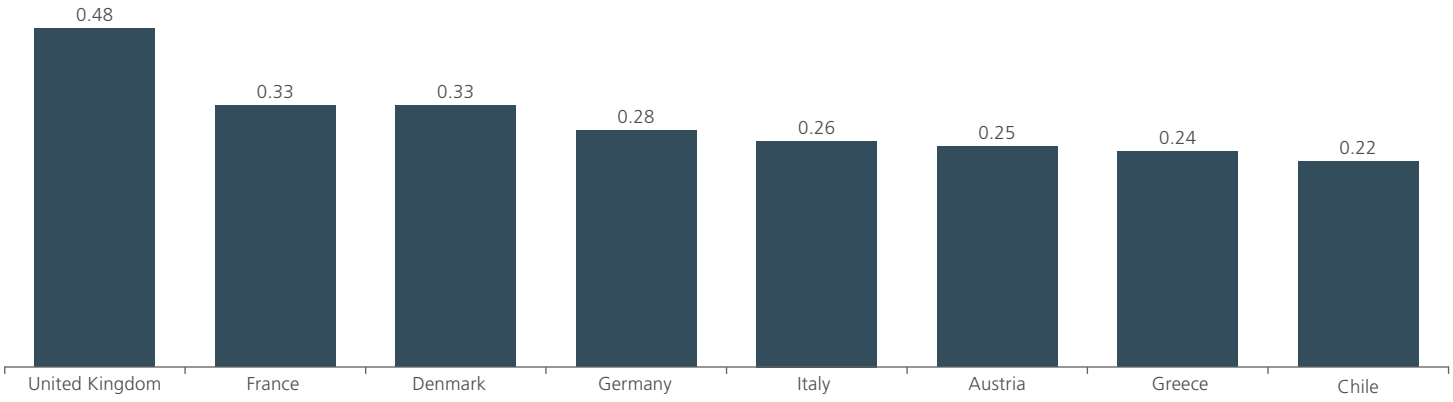
Per 100,000 inhabitants



*It considers only women ages 15 and up
Source: Colégio de Matronas

Figure 17
Midwives (matronas) per capita by selected countries (2018)

Number of professionals per 1,000 people



Source: OECD

"… The problem is that the patient needs to wait two, three months to get a consultation. Each matrona covers a huge number of patients…"

APS, Copiapó

3. Limited professional experience with breast cancer

Many primary care professionals have limited experience in assessing patients with breast cancer, and lack full knowledge of the coverage guidelines, especially regarding mammography.

"… At the university, matronas learn mainly about obstetrics and reproductive care; they know very little about specific diseases such as breast cancer …"

UPM, Santiago

The problem has mainly three causes. First, undergraduate students have low exposure to breast cancer during their studies, mainly because the curriculum of several universities in Chile does not cover the pathology in detail and does not provide many internship opportunities at UPMs (breast pathology units).

Second, there is a lack of formal training on breast cancer for primary care professionals already working in public clinics. Therefore, these professionals are not up to date on clinical and coverage guidelines, which affects their ability to properly assess and refer patients. Moreover, limited human resources in the primary care units also prevents professionals from completing specializations and other training, as they lack time during working hours.

Third, in many regions there is no interaction between primary and secondary care units, which is key to knowledge sharing and to the training of matronas and primary care physicians.

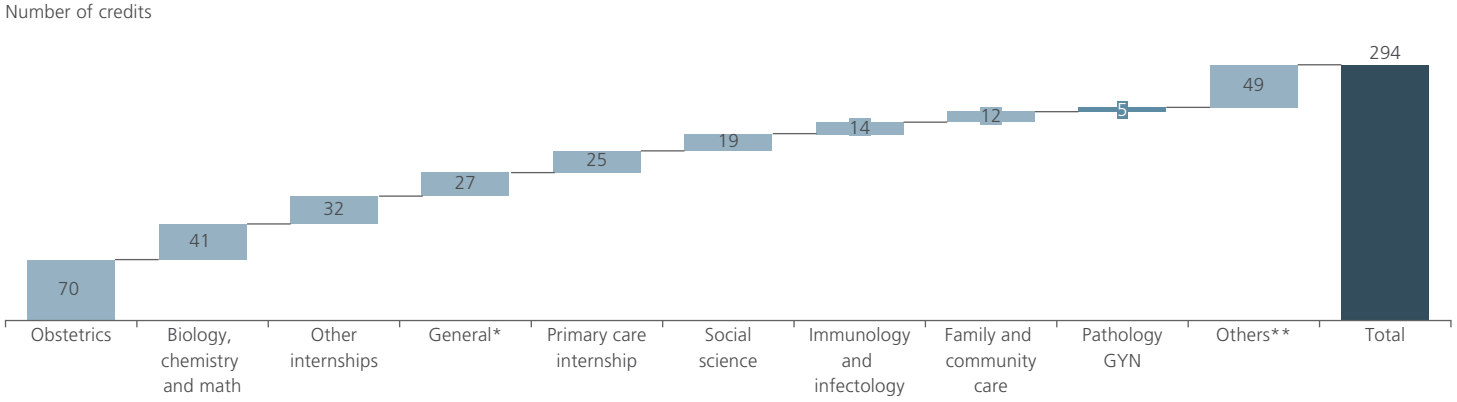
All these factors lead to improper assessment and incorrect referrals to secondary care of patients who do not have a suspicion of breast cancer, which gets in the way of providing care to women in actual need.

4. Limited access to high-quality screening and confirmatory exams

Both physical and human infrastructure to perform mammography and additional confirmatory imaging exams, especially echography, is very restricted in the public system.

Figure 18

Timetable of undergrad program of matronas (2019)



Notes: * Includes subjects that are common across all undergrad programs, such as English, social commitment, physical education, etc.; ** Includes pharmacology, management, research and others

Source: Universidad de Chile, L.E.K. interviews and analysis

"… No APS here has equipment. There are two [machines] in hospitals, but they are only used for their patients; the women at the consultations cannot access it [them] …"

APS, Copiapó

"… Echography availability is very limited. This year, our exam quotas ended in May …"

APS, Santiago

The lack of public screening infrastructure limits the availability of exams and prevents the government from creating policies to support broader screening coverage, today restricted to women between 50 and 69 years old. [21]

"… Although mammography is a critical step in the patient flow, equipment is limited …"

UPM, Santiago

Because the provision of exams for some women is mandatory under GES guidelines but the public system lacks sufficient mammography equipment, municipalities outsource exams to private centers. However, in many cases this practice is not beneficial, since municipalities tend to choose price over quality because of budget constraints, and many private providers lack high-quality machines and specialized radiologists.

"… Mammography exams have very poor quality. Many private radiology centers are uniquely chosen on cost, which doesn't incentivize them to invest in high-quality equipment …"

UPM, Santiago

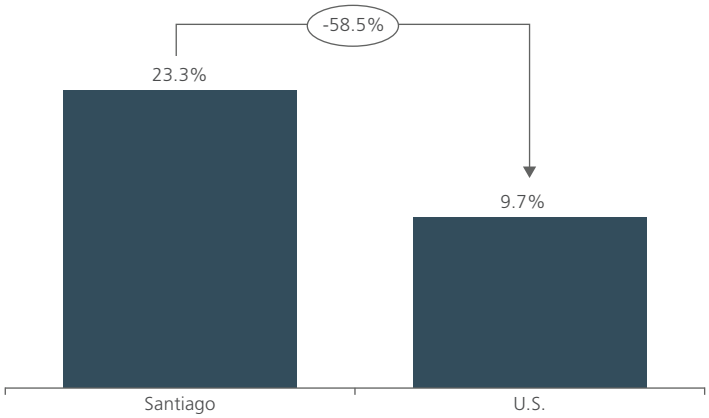
"… The comunas normally choose price over quality. Many times we need to redo all exams because we don't trust the results …"

UPM, Copiapó

The poor quality of the infrastructure results in a high number of inconclusive results, which necessitate additional imaging exams to confirm the suspicion of breast cancer. This additional requirement not only increases costs to the government, but also limits patients' access to diagnosis, as there is a lack of infrastructure in the system and patients cannot proceed in GES without a confirmed suspicion.

Figure 19

Inconclusive mammography results,* Santiago vs. U.S. (2019)



*BI-RADS 0 and 3

Source: National Radiology Data Registry, REM

"… Echography is important to validate the suspicion, but patients outside the group risk need to wait up to a year. There aren't enough resources for everyone …"

UPM, Valdívia

"… Many of the delays in diagnosis are due to the waiting time for echography; it is long because it depends on a radiologist to do it …"

UPM, Rancagua

5. Limited incentives and public policies for risk assessment and screening

Today, there are no government incentives and sanitary targets to perform mammography exams as part of a broader screening policy, as happens for other exams, such as Pap smears. Therefore, healthcare professionals usually do not recruit women for mammography and tend to prioritize other conditions during the limited consultation time, substantially impacting the number of women properly assessed.

Moreover, there is an important mismatch between GES recommendations and the actual coverage policies. The first inconsistency involves the free mammography coverage age. Although the GES guidelines for breast cancer recommend a mammogram every two years for all women between the ages of 50 and 74, the existing national coverage policy ensures a free mammogram only every three years and only for women between 50 and 69.

Figure 20
Section of GES guidelines on breast cancer (2015)

RECOMENDACIONES CLAVE

RECOMENDACIONES	Recomendación
Se recomienda promover una alimentación baja en grasas, disminuir el consumo de alcohol y aumentar la actividad física factores que contribuyen a disminuir el riesgo de desarrollar cáncer de mama.	C
Realizar tamizaje cada 2 años con mamografía en mujeres de 50-74 años, asociado o no a EFM.	B
Evaluar los factores de riesgo mayores y menores para identificar y clasificar a las mujeres de alto riesgo.	B
Detectar y derivar los casos sospechosos de patología maligna de la mama a especialista.	B

Source: Minsal

Figure 21
Resolución Exenta 1315 (2016)

El Programa Nacional de Pesquisa y Control del Cáncer de Mama, cuenta con una Red de atención en la patología de mama, la cual además es una patología perteneciente al GES, garantizando prestaciones desde la confirmación diagnóstica por especialista, tratamiento, seguimiento y paliación, cuando corresponda.

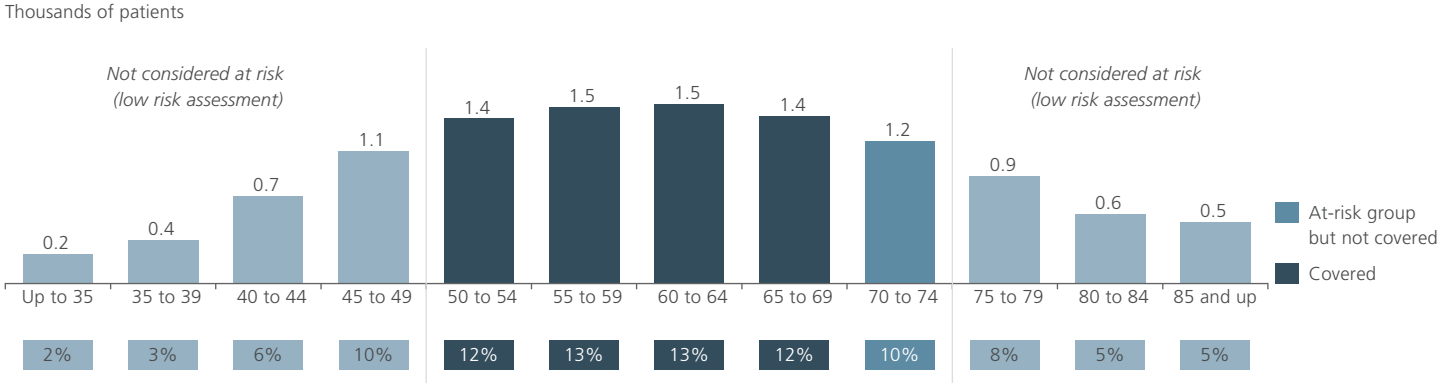
En la atención Primaria de Salud, el Programa de Imágenes Diagnóstica permite focalizar la realización de screening gratuito de mamografía a mujeres 50 a 69 años, cada 3 años, además de ecografías mamarias y magnificaciones en casos específicos.

SUBSECRETARIA DE REDES ASISTENCIALES SUBSECRETARIA

2. **Detección precoz de Displasia luxante de caderas (DLC) a través de servicios de imágenes:**

Source: Minsal

Figure 22
Total potential breast cancer patients by age, Chile (2019)



Source: Minsal

This policy is not only controversial, but also extremely restrictive, since 50% of the potential breast cancer patients are outside the age group covered, as shown in Figure 22.

Another inconsistency involves genetic testing. Even though the official guidelines acknowledge that women who have an inherited mutation in the BRCA1 or BRCA2 gene are at increased risk of developing breast cancer, the existing policies do not cover BRCA tests to identify these women.

"… The population at risk is not identified since there is no possibility of doing BRCA because it's not covered by government regulations …"

UPM, Valdívia

On top of that, the current guidelines are not properly promoted to professionals, who consequently do not have a clear view of who is covered. For example, during our interview campaign several professionals failed to correctly identify which women have the right to free mammography.

6. Low levels of patient support and system coordination

There are two main barriers that span all steps of the patient journey, impacting patients from the initial consultation through treatment.

The first barrier is the lack of support for patients. In general, patients have insufficient information about the disease, their rights and the services available, as well as about available psychological support to deal with a cancer diagnosis. Consequently, some women abandon the diagnosis and treatment process.

The second barrier relates to suboptimal usage of public resources. Whereas some Servicios de Salud have relatively high budgets given the additional funds provided by comunas, others suffer from lack of resources and cannot access the same equipment and human resources even when these resources are available. Such a situation exists, for example, in Santiago, where some Servicios de Salud have great infrastructure, while others struggle to provide basic services.

Improving prognostics: a common responsibility

Although much has been done for Chilean patients, there are still important barriers to be addressed to improve the prognostics of breast cancer.

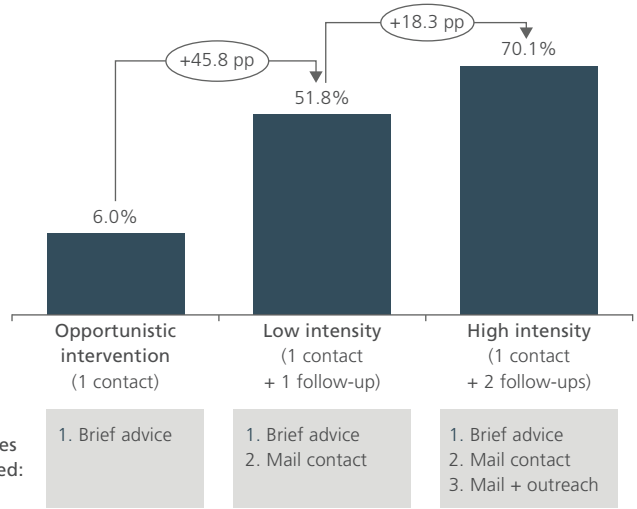
Addressing the barriers, and consequently reducing the burden of breast cancer in Chile, requires joint efforts from the government, the private sector and society in general to develop a comprehensive action plan.

1. Prevention culture and awareness

According to the vast majority of specialists interviewed during our campaign, in order to increase awareness, breast cancer demands constant campaigns, which are most effective when locally planned and executed to respect regional specificities and address regional informational gaps.

Indeed, K. Puschel and B. Thompson (2011) demonstrated, in research done in Santiago, not only that it is possible to substantially increase mammography rates through awareness campaigns, but also that responses exponentially increase with the frequency and intensity of the messages, suggesting that greater investments in disease education are likely to have positive results.

Figure 23
Mammography conversion rate by intervention intensity, Santiago (2011)



Source: Puschel K. and Thompson B. (2011)

Yet the public infrastructure is saturated, and healthcare professionals do not have time and resources to educate the population alone; hence, there is a need for shared responsibility among distinct parts of civil society. In this context, partnerships between the comunas, Servicios de Salud and third-party institutions such as universities, patient associations, NGOs, and private companies may be a viable alternative to support primary care providers in organizing and promoting educational events and awareness campaigns throughout the year.

Although multiple approaches exist, local events in APS or other community locations and media campaigns — for example, on radio — are two successful examples that could be replicated throughout the country.

Local awareness campaigns The case of Yo Mujer

Yo Mujer organized a local awareness campaign about breast cancer in Toconao, a city in the extreme north of Chile. This initiative was a joint effort between Yo Mujer, a local private company and the nearby municipalities, which together allocated resources to promote the event on local radio and to provide free transportation and food to the participants. As a result, the event attracted more than 100 women, who had the opportunity to learn about the importance of prevention and hear the testimony of a real patient.

2. Primary care enhancement

The limited experience primary care professionals have with breast cancer means there is an urgent need to promote education about the pathology.

There are many ways to address this barrier, but we recommend three, based on successful local and international benchmarks.

The first approach is to develop a closer relationship between primary and secondary care, through the annual meetings, in order to promote knowledge sharing and reduce the number of incorrect referrals to the UPMs, a strategy that has been successful in Los Ríos.

UPM and APS annual meeting
The case of Los Ríos

The Servicio de Salud of Los Ríos, together with the UPM in Valdivia, organizes an annual event to promote breast cancer awareness among primary care providers. In a full-day session, UPM specialists present to the APS matronas a summary of the key facts of that given year and conduct workshops on topics such as breast imaging interpretation. Apart from the knowledge sharing, the event leads to important discussion about the main challenges faced by APS providers and ways to overcome patient barriers to care.

Workshops run at the UPMs by specialists have also been very successful in educating APS matronas, who learn about all the steps of breast cancer diagnosis and treatment and gain real-life experience with patient assessment.

The second approach is to foster the use of distance learning to educate primary care professionals, as online channels are relatively cheap and flexible compared to traditional approaches, such as in-person classes.

The public administration has already adopted this strategy, offering a platform with many cápsulas educacionales that cover multiple pathologies and other topics related to the healthcare system.

However, according to the specialists we interviewed, the platform is not widely promoted and contains too many videos, which makes it hard for professionals to select relevant content and stay engaged with the learning process.

Therefore, there is an opportunity to revamp the government learning program by reviewing the number and content of the videos and promoting them more, potentially on nongovernment platforms such as YouTube and Vimeo.

The third approach is better supporting the education of primary care professionals at the beginning, by working with universities. We believe there is room to review current curricula to increase students' exposure to breast cancer-related subjects and to increase the availability of practical activities at the UPM, via internships and preceptorship programs.

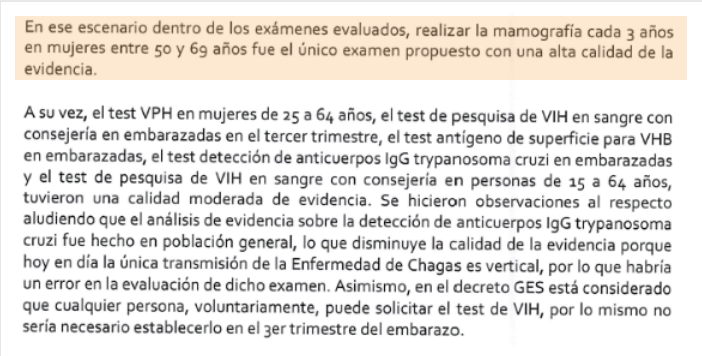
Pasantías at UPM
The case of Universidad de Valdivia

The Universidad de Valdivia, in partnership with the Hospital de Valdivia, offers all its obstetrics students the opportunity to rotate through all the hospital departments. During their rotation in the UPM, students take part in consultations with cancer patients, have educational workshops with specialists, and learn about the administrative processes of the UPM and the main roles of UPM matronas.

3. Investment in high-quality screening

Minsal executives acknowledge the effectiveness of mammography in detecting breast cancer in its earliest stages of development. In one of the meetings of Consejo Consultivo Garantías Explícitas en Salud Ley 19.966, the participants agreed that among all the pathology screening protocols under discussion, mammography was the only one with high evidence of efficacy (see Figure 24 below).

Figure 24
Section of the minutes from Consejo Consultivo GES (2019)


En ese escenario dentro de los exámenes evaluados, realizar la mamografía cada 3 años en mujeres entre 50 y 69 años fue el único examen propuesto con una alta calidad de la evidencia.

A su vez, el test VPH en mujeres de 25 a 64 años, el test de pesquisa de VIH en sangre con consejería en embarazadas en el tercer trimestre, el test antígeno de superficie para VHB en embarazadas, el test detección de anticuerpos IgG trypanosoma cruzi en embarazadas y el test de pesquisa de VIH en sangre con consejería en personas de 15 a 64 años, tuvieron una calidad moderada de evidencia. Se hicieron observaciones al respecto aludiendo que el análisis de evidencia sobre la detección de anticuerpos IgG trypanosoma cruzi fue hecho en población general, lo que disminuye la calidad de la evidencia porque hoy en día la única transmisión de la Enfermedad de Chagas es vertical, por lo que habría un error en la evaluación de dicho examen. Asimismo, en el decreto GES está considerado que cualquier persona, voluntariamente, puede solicitar el test de VIH, por lo mismo no sería necesario establecerlo en el 3er trimestre del embarazo.

Source: Minsal

Moreover, the current government has included expanding access to mammogram machines in the Plan Nacional de Cáncer. The government has invested in 31 new machines that will be distributed to 13 regions of Chile.

Although this is good progress, it is not sufficient, especially in the short term. There is a need to increase the annual budget to outsource exams to the private sector at the same time that investments are made in new machines and in training professionals in order to create a sustainable scenario moving forward.

In addition to increasing the system's capacity, it is pivotal to secure the quality of exam results, especially in a scenario in which the vast majority of exams are done in private centers, as happens today.

Among all possible initiatives to address this issue, we recommend three: establishment of a certification for radiology centers, refinement of the auction terms to select a provider and change in the procurement schemes.

The first proposal is not new. A few years ago, some institutions, together with Minsal, discussed the development of a national certification to audit radiology centers to set standards of quality. Unfortunately, there was disagreement between the institutions, and the plan was archived. Although the reasons for the disagreement remain unknown, we believe that conversations should restart, aiming at better patient care.

Although the need for quality certification supports the outsourcing of exams, that is not the only possible approach. Currently, many comunas do not include quality criteria in their auction terms, a reality that should be changed moving forward. Not only should private providers prove their capacity to deliver high-quality exams in order to be considered for the auction process, but there also should be clauses to terminate a contract if the provider does not deliver the expected results.

Lastly, there is also an opportunity for a complete change in the procurement scheme, switching from the fee-for-service (FFS) approach to an episode-based scheme, in which Servicios de Salud would procure not just a single exam, but a result for a suspicion, including confirmatory exams when needed. Through this method, the government would incentivize the centers to increase the quality of the exams, as retakes generate additional costs, and to reduce the wait time for confirmatory imaging in public services.

Schemes that incentivize performance are already a reality in other countries and are expected to become increasingly prevalent around the globe.

Value-based care model
The case of CMS

The Centers for Medicare & Medicaid Services (CMS) is one of the most important payers in the U.S. and has developed the End-Stage Renal Disease Quality Program to improve services in dialysis facilities. This program is unique in that part of CMS' payment to providers is based on their performance and on the quality of the service provided. This has allowed CMS to reduce its payments to facilities that do not meet the stipulated performance standards.

4. Patient support programs

Although there are multiple associations and individuals dedicating time and resources to making the lives of breast cancer patients and their families easier, there is still an opportunity to increase support to Chilean women, especially in the initial stages of their journey toward a cure.

Patients lack knowledge about the disease, the optimal diagnosis process and their rights. These institutions can play a pivotal role in enhancing Chilean women's access to healthcare services and in providing them with psychological support, helping patients stay on the path of diagnosis and treatment.

It is important to broaden the scope of these institutions and provide tools to professionals to help them support the patient from the beginning of her journey, which will be possible only through higher investment and more knowledge sharing.

Patient Support Program
The case of Genentech

Genentech is an American institution that has helped more than 1.5 million patients access their medicines. It helps insured patients navigate the bureaucratic steps of coverage by informing them about their rights and helps patients who cannot afford the treatment by referring them to a foundation for financial support.

The time to act is now

Each year, more than 5,300 Chilean women with breast cancer fail to receive even a proper diagnosis — let alone treatment. We can wait no longer to change this situation.

Although many barriers to breast cancer diagnosis and treatment exist, there are multiple examples of regions inside and outside Chile that have circumvented them successfully, and their efforts can be replicated.

We are confident that through the joint efforts of the government, private companies and the third sector, Chile can dramatically improve its current prognostics and reduce the burden of breast cancer on women.

Given the lack of reliable and updated epidemiological data, we have developed a proprietary model to estimate the potential number of new breast cancer cases per year. In general terms, the model adjusts crude (non-adjusted) incidence rates in the U.S. for age, gender and ethnicity profiles of the Chilean population, considering regional aspects of the country. The model has five steps:

1. Assessment of crude (non-adjusted) incidence rates in the U.S., using SEER records; data provided by age, gender and ethnic profile
2. Segmentation of Chilean population by age, gender and ethnic profile, and by region, considering penetration of indigenous and "mestizo" populations.
   - Segmentation runs based on data from INE, FONASA, World Atlas, Latinobarómetro report and Revista Médica de Chile
3. Matching of U.S. and Chilean population "segments" (i.e., age, gender and ethnic profile)
4. Adjustments of U.S. incidence rates for Chilean population segments
5. Calculation of potential number of patients based on number of people in each segment

The U.S. was selected as the benchmark because of its efficient healthcare system for cancer diagnosis (with similar diagnosis rates to those in European countries) and the availability of reliable data.

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Authors

Maurício França
Partner,
Biopharma and Life Sciences practice
São Paulo, Brazil

Sue St. Sure
Partner,
Biopharma and Life Sciences practice
Los Angeles, California

Brian Baranick
Partner,
Biopharma and Life Sciences practice
Los Angeles, California

Tian Han
Principal,
Biopharma and Life Sciences practice
Los Angeles, California

Rafael Freixo
Consultant,
Biopharma and Life Sciences practice
São Paulo, Brazil

Daniel Ito
Associate Consultant,
Biopharma and Life Sciences practice
São Paulo, Brazil

Fernanda Lisboa
Associate,
Biopharma and Life Sciences practice
São Paulo, Brazil