



Breast Health Care System Assessment

SAO PAULO, BRAZIL, MAY 2012



John Snow, Inc.

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Executive Summary

In the past two decades, Brazil has made good progress on many health indicators and health systems development. However, challenges remain, particularly in the areas of non-communicable diseases, and geographic and social equity. This report focuses in one important area—breast cancer. Breast cancer is the most significant cause of cancer mortality and morbidity among women in Brazil today. Progress is being made by the Ministry of Health, State and Municipal Health Authorities, and Non-Governmental Organizations (NGOs) to improve early diagnosis, promote breast cancer screening and foster public education. However, more needs to be done and can be done in combined approach to increasing early detection and treatment of breast cancer and optimizing the organization of breast cancer care. Particularly urgent is analysis and strategy development—by both community and public health leaders—of systems, financial and environmental/patient barriers to access and care.

The Susan G. Koman for the Cure is the world’s largest breast cancer advocacy and care network of survivors and activists. The Foundation partners with Government and NGOs in Brazil to combat breast cancer. As part of its grant from the Caterpillar Foundation to work in Brazil, this report provides an overview of the current situation in Sao Paulo City and highlights the opportunities for the Foundation, government and non-governmental organizations to improve breast health care in this city.

The methodology used in this assessment included a comprehensive desk review from a large range of data sources (WHO, PAHO, World Bank, GLOBOCAN, LAEA, and national data information systems, DATASUS, SIMS and SISMANA, plus further sources from within Brazil), key informant interviews and site visits in Brazil. A mapping exercise of Sao Paulo municipality was undertaken to understand and visualize availability of breast cancer screening resources and compare service data with demographic and socio-economic data.

Eighty percent of Brazil’s 195 million people live in urban areas, with the population heavily concentrated in the industrialized Southeast Region. Brazil is classified as a middle income country, and total health expenditures per capita are \$734, or 9.0 percent of GDP. Sao Paulo, the focus of this report, has over ten million people and is Brazil’s largest city. It also is the largest health care hub in Latin America, with many of the best public and private hospitals.

There are three subsectors in Brazil’s large and complex health system—public, private and insurance sectors. The largest sector is the public health system, which is defined and mandated by a series of public laws and called the Integrated Public Health System, or Sistema Unico de Saude (SUS). SUS is administered at the federal, state and municipal levels. The point of entry for clients is primary health care “basic health units” (UBS). Sao Paulo municipality has 246 such units and 1,196 family health teams. These units are responsible for breast health education, clinical breast examination, promotion of mammography screening and referral.

Secondary and tertiary care for breast cancer (diagnostics and treatment) is provided at public and private sector facilities, financed through both public and private mechanisms. Private health insurance is provided through a variety of forms. It covers some 37 million Brazilians and also is concentrated in the industrial Southeast Region.

Financing of the Brazilian health system is mixed; public and private sources of financing coexist. Public financing covers 46 percent of total health expenditures, with insurance and out-of-pocket expenditures covering the rest. Disaggregated data on financing breast cancer programs is not available. However, cancer-specific data on financing is available and shows a steady increase in expenditures. Issues do exist with budgeting and allocation of expenditures, although financing system efficiency appears to have improved in recent years due in part to outsourcing services to third party providers.

In Brazil, breast cancer is the leading cause of cancer mortality in women. Incidence is similar to that of high income countries. Approximately one third of the estimated 52,680 cases of breast cancer in Brazil in 2012 will occur in the State of Sao Paulo, and

the city alone will need to respond to 6,000 new cases. Age-adjusted mortality rates for breast cancer are on an upward trajectory; 2009 rates in the Southeast were 12.6 deaths per 100,000 women. Stage at diagnosis remains an important concern. Recent studies report that 20.2% of patients are diagnosed in stage I; 46.8% in stage II; 24.6% in stage III; and 5.5% in stage IV.

An analysis of the organization of breast health service delivery points to issues in coordinating care. Cancer care through SUS is organized through state or regional referral centers. National Oncological Care is defined and proscribed by federal law, which sets standards for care. Care is provided at medium or high complexity units, but care is characterized by delays at every level due to increased demand and fragmentation of services. The median time lapse between mammography and diagnosis, for example, is said to be 60-120 days. Facilities that provide a range of services (i.e. education, screening, diagnosis, treatment, and follow-up care) in one place are very limited.

The Brazil Ministry of Health national guidelines recommend mammography screening every two years for women aged 50-59 and every year starting at age 35 for women with a family history of breast cancer. Sao Paulo follows recommendations on screening, and data show increase in screening mammography. These improvements in one-time and recent mammography use are encouraging, but diagnosis is still frequently at later stages, and there is low adherence to guidelines on repeat mammography.

Mapping data (see methodology) suggest potential equity issues related to breast cancer early diagnosis and treatment. A large portion of the services are concentrated in the Central Zone of Sao Paulo municipality, and wealthier areas are far better covered than socially deprived areas, despite high population densities. Further study is needed to determine breast cancer incidence by ethnicity, level of deprivation, and geographic proximity to services; however, initial data suggest alternative strategies, such as planned mobile mammography, could improve equity.

Breast cancer surgeries are mainly conducted at specialized tertiary level and reference hospitals of Sao Paulo Municipality. The development of radiotherapy treatment is an important priority for the federal government. Tamoxifen is widely available for adjuvant therapy. Substantial differences exist in regimens used for adjuvant chemotherapy. Access to anti-HER2 therapy is very restricted in the public sector system, although Sao Paulo State is the exception due to recent decisions to reimburse expensive medicines. Palliative care is underdeveloped in Sao Paulo municipality and is typically managed in oncology units by medical oncologists.

Sao Paulo has two cancer registries, the Population-based Cancer Registry (PBCR) and Cancer Hospital Registry, which is assigned to the Oncocentro Foundation of Sao Paulo (FOSP). Informants question the completeness and quality of cancer registry data, and find it user unfriendly. It is not being used systematically for decision-making.

The assessment concluded that Brazil in general and Sao Paulo City specifically have made remarkable progress in addressing breast cancer, but that challenges and gaps remain. These are, however, surmountable. The assessment team identified cross-cutting constraints across the breast health care system components which are translated into following key recommendations and most of the health professionals interviewed welcome a partnership that can help strengthen these various areas:

- Study and address (incentives, location of facilities, public education) potential geographic and socio-economic inequities in service delivery access in specific areas and sub-populations of Sao Paulo City.
- Study further and strategize ways to address fragmentation of services, particularly needed improvements to the referral system and increase patient-oriented and focused care.
- Provide technical assistance and support to the FOSP's technical committee in developing effective policies and reorganizing referral systems.
- Explore development of "One-stop" breast health clinics.

- Expand patient navigation systems.
- Empower Family Health Teams and UBS to become more proactive in community education and facilitation diagnostic and care services throughout the continuum of breast care.
- Continue and expand public awareness and community involvement activities in breast cancer through a variety of mechanisms.
- Increase use breast cancer data from registries and other information systems for decision-making

I. Introduction

During the past two decades, Brazil has made significant progress in developing a dynamic, complex health system towards its ultimate goal of universal, equitable, and sustainable health care. Despite this progress, Brazil's health system faces significant challenges, particularly increases in non-communicable diseases, geographic and social inequalities, and assuring quality of care and safety of patients. Non-communicable diseases are the largest contributor to the burden of disease, and cancer is the second leading cause of death after diseases of the circulatory system.¹ Because of these challenges, NCDs are rapidly becoming the main public health priority in Brazil.

Breast cancer is the most frequently diagnosed cancer in women in Brazil. The mortality has increased, and breast cancer is now the most common cause of death from cancer in women. Increased public awareness of breast cancer and expansion of access to screening are important public health strategies to reduce breast-cancer mortality. Efforts are now under way by the Ministry of Health in Brazil and non-governmental organizations to improve early diagnosis, promote breast cancer screening and public education. The Ministry of Health developed National Breast Cancer Early Detection Program. However, much more urgently needs to be done.

Identifying barriers to early detection and treatment is a critical component of breast cancer control programs. Barriers include: system barriers (such as lack of infrastructure, insufficient training of staff, and logistical barriers), financial barriers (such as expense of drugs and diagnostic and radiotherapy equipment) and environmental or patient barriers (such as lack of transportation or knowledge about appropriate and successful treatment). To improve breast cancer morbidity and mortality, analyses of these barriers must be undertaken, and strategies developed to overcome. This process needs to involve both community and public health leaders.

In 2011, Susan G. Komen for the Cure received a grant from the Caterpillar Foundation to build on the work of the foundation taking place in Brazil. As part of this grant, funds were allocated to complete assessment in Sao Paulo City. The Susan G. Komen Breast Cancer for the Cure is the world's largest breast cancer organization fighting to save lives, empower people, ensure quality care for all and energize science to find the cure.

This report provides an overview of the burden of breast cancer and breast health care system in Sao Paulo City. The report highlights achievements, opportunities and most promising areas that Susan G. Komen for the Cure, Sao Paulo local government authorities, local foundations and Non-Governmental Organizations (NGOs) can invest in and support in order to improve the breast health care in Sao Paulo.

¹ Maria Inês Schmidt et al. *Chronic non-communicable diseases in Brazil: burden and current challenges. The Lancet, Volume 377, Issue 9781, Pages 1949 - 1961, 4 June 2011*

II. Methodology

The assessment methodology consists of analyses of the Brazil's performance according to a set of internationally recognized indicators carried out through a review of available literature and statistics, key informant interviews, and visits to selected health care facilities to gain further information and data.

The first phase of the assessment of breast health care system in Sao Paulo City consisted of desk research and analysis. Background documents about Brazil's health system and cancer (specifically breast cancer) were identified via Internet research, recommendations from the local stakeholders. Key informants were contacted prior to visit to Sao Paulo. Data from WHO, PAHO, World Bank, GLOBOCAN, IAEA and other international sources were compiled. The national data information system, DATASUS, SIM, SISMAMA were consulted to obtain breast cancer specific information.

The assessment team held consultation with the Susan G. Komen for the Cure to develop assessment framework to identify priority areas of concentration and key informants.

The second phase of the assessment included a country visit and interviews with key stakeholders. These interviews were hand-recorded by the interviewers in notebooks and examined to identify response patterns across stakeholders. The team also collected further documents and relevant data from various sources within Brazil.

The methodology also included a mapping exercise aimed at identifying geographical gaps in the provision of breast health care services in Sao Paulo municipality. The mapping combined breast health care service provision data with demographic data, including population density and social deprivation, to give a clearer picture on distribution of breast health care services. Information on the facilities and numbers of procedures performed by each facility was provided by the Sao Paulo State Health Secretariat. Two pieces of mapping software, Google and ArcGIS were used to complete the mapping exercise.

III. Background

COUNTRY OVERVIEW

Brazil is the largest country in Latin America, with a population of approximately 195 million, according to the 2010 census. Based on World Bank criteria, Brazil is categorized as a lower middle income group country.

It is a federative republic comprised of 26 Federative Units (States), and one Federal District (Brasilia). The country is further divided into five distinctive regions (north, northeast, center-west, southeast, and south), and has more than 5,500 municipalities. The majority of the Brazilian population (80 percent) lives in the urban areas, predominantly in the cities (46 percent) located in the more industrialized southeast region (Sao Paulo, Rio de Janeiro, Belo Horizonte, and Espirito Santo).

About eleven million people, more than half of them women live in the country's largest city, Sao Paulo.

The country is characterized by a rapidly growing economy and significant demographic transition in recent years. For example, economic growth was 7.5 percent in 2010, although it slowed in 2011. Further, the population growth rate has declined rapidly in the last 9 years from nearly 2 per cent in 1990 to 1.2 per cent in 2010.² That new Brazilian fertility rate, 1.9 children per woman, is below the level at which a population replaces itself. Of the total adult population, 0.42% lives with HIV/AIDS. There are 17 infants' deaths for each 1,000 births and 58 maternal deaths per 100 000 live births.³

Total health expenditures per capita are 734 US\$ making the proportion of the health budget to GDP 9.0%. Non communicable diseases are now the predominant cause of mortality in Brazil, with circulatory system diseases being a more important contributor to overall mortality, followed by cancer and external causes (homicides and traffic accidents)⁴.



Regions and states of Brazil

SELECTED ECONOMIC INDICATORS	
GDP per capita (International dollar, 2010)	\$10,710
Annual GDP growth rate, 2010	7.5%
Population below the national poverty line, 2009	21.4%
Total expenditure on health (as a % of GDP 2010)	9.0 %
Public/private breakdown of health expenditure	4.1 / 4.9
Per capita total expenditure on health (2009)	\$ 734
Per capita government expenditure on health (2009)	\$ 280
Out-of-pocket expenditure as % of private expenditure on health (2009)	57%
GINI index	54%

² Instituto Brasileiro de Geografia e Estatística. http://www.ibge.gov.br/home/presidencia/noticias/noticia_visualiza.php?id_noticia=1866&id_pagina=1 (accessed February 14, 2012)

³ The World Bank. World Development Indicators, <http://data.worldbank.org/country/brazil> (accessed February 10, 2012)

⁴ Paim J, Travassos C, Almeida C, Bahia L, Macinko J. The Brazilian health system: history, advances, and challenges. *The Lancet*, Volume 377, Issue 9779, Pages 1778 - 1797, 21 May 2011

SELECTED DEMOGRAPHIC AND HEALTH INDICATORS

Total population estimate (2010)	195,947 million	195,947 million
Annual population growth rate (2009)	1.2%	1.2%
Total fertility rate (per woman) estimated (2001/2012)	2.3	1.9
Maternal mortality (2008)	58/100,000 live births	58/100,000 live births
Infant mortality (2010)	17/1,000 live births	17/1,000 live births
Life expectancy	73 years	73 years
Women of reproductive age ⁵ (15 to 49 years)	53,668 million	53,668 million
Contraceptive prevalence (any method) (2009)	80%	80%
Pregnant women receiving prenatal care	97%	97%
Prevalence of HIV (2010)	.42%	.42%
Exclusive breastfeeding (% of children under 6 months) (2006)	40%	40%
Obesity %	47%	47%
Total Alcohol Drinkers %	19%	19%

Sao Paulo has a population of 10 314 057⁶ which makes it the largest city in Brazil, the largest city in the southern hemisphere, and the world's seventh largest city. Sao Paulo is the capital of the state of Sao Paulo, which is the most populous Brazilian state. It exerts strong regional influence in commerce and finance as well as arts and entertainment.

The city of Sao Paulo is divided into 31 sub-prefectures, and each in turn is divided into 96 districts. The sub-prefectures are officially grouped into nine regions (or "zones"). The nine regions are used only for bureaucratic purposes by governmental agencies and are not identified by any visual communication in the city.

Sao Paulo is the largest health care hub in Latin America. The city is home to institutions from all the three levels of government-- federal, state and municipal. The private health care sector is also large and influential; most of the best hospitals in Brazil are located in the city. These include hospitals such as Albert Einstein Israelites Hospital, ranked as the best in Latin America, and the Hospital das Clínicas. Detailed information about organization of health care in Sao Paulo City, including the breast health care system, is provided in different sections of this report.

OVERVIEW OF BRAZIL'S HEALTH SYSTEM

The Brazilian health system is made up by three subsectors. The largest is public subsector called the **Integrated Public Health System or Sistema Único de Saúde (SUS)**. Based on the 1988 federal Constitution and regulated by Law 8.080 and Law 8.142 (since 1990), the SUS was established with the objective of improving access to health services and quality of care, as well as enhancing the country's overall health situation. The SUS basic mission is to guarantee free and complete primary health care or "basic care" as it is called in the SUS, to the entire Brazilian population and ensure universality, equality and integrality of the health services.

The system is organized in a decentralized manner, with health actions articulated among the three spheres of administration: Federal, State and Municipal. Provision of health services is the responsibility of municipal governments, financially aided by the federal government and the states. However, all services operate within a unified system, given that all levels of services cannot be provided at the municipal level. The SUS incorporates health posts, hospitals, university health centers, laboratories, blood banks, as well as research centers.

⁵ Instituto Brasileiro de Geografia e Estatística. 2010 Population Census. <http://www.ibge.gov.br/english/estatistica/populacao/censo2010/default.shtm> (accessed March 12, 2012)

⁶ Instituto Brasileiro de Geografia e Estatística. 2010 Population Census. <http://www.ibge.gov.br/english/estatistica/populacao/censo2010/default.htm> (accessed March 12, 2012)

The main entry point for patients seeking care at the primary health care level in the public health system is the UBS, or Unidade Básica de Saúde (Basic Health Units). These units are established across Brazil and receive higher priority than other levels of care as part of the ongoing health care reform. The basic health units work hand in hand with the Family Health Strategy (FHS)⁷. FHS works through family health care teams, composed of one doctor, one nurse, one auxiliary nurse, and for to six community health workers. The focus of UBS/FHS system is on lower-income families and communities and integration of medical care with health promotion and public health actions.

Duties and activities of the UBS/FHS also include breast health education, clinical breast examination, promotion of mammography screening and referral. As part of the FHS approach, teams of community health workers are trained to work in direct contact with the community in all Brazilian cities. Sao Paulo municipality has 246 UBS units with 1196 established family health teams (about 30% coverage) in Sao Paulo city to cater basic health care for the population at the community level (Map 1).

For the secondary care and specialized procedures, SUS often relies on contracts with the private sector, especially for diagnostics services, by the means of a referral process to a secondary or tertiary health service delivery point or a hospital. More complex and high-cost procedures are done predominantly by contracted private sector providers and at public teaching hospitals, paid by the SUS.⁸

The **second subsector** in Brazilian health system is the private, represented by specialist diagnostic and therapeutic clinics and private hospitals, in which the services are financed by both public or private sources. Private sector involvement in the SUS is said to be complementary and provided in the form of contracts and service agreements when the public health system does not have the capacity to provide services for all the population in a particular region.

Finally, the **private health insurance subsector** is large and complex, with different forms of health plans (such as voluntary plans, group health plans, self-managed health plans, with employee enrollment), varying insurance premiums, and tax subsidies. In 2007, more than 37 million Brazilians had private health insurance. The private health plans and insurance market is concentrated in the southeast region, where about 62% of health companies are based.⁹ People with private health plans or insurance policies have better access to preventive services and tend to have higher health-care use rates than those without such plans. However, public health care is still accessible for people who choose to obtain private health insurance, so they often receive high-cost services and complex procedures because insurance packages do not always cover the full range of services.¹⁰ On the other hand, approximately 48% of the total population exclusively uses SUS services.

Financing of the Brazilian health system is mixed; public and private sources of financing coexist.¹¹ Public financing covers nearly 46 percent of the total health expenditures¹², originating in general taxes in the three government spheres and in social contributions (federal). For example, the federal government covered a little more than 50 percent of the total for the public system in 2004; states contributed nearly 27 percent and municipalities 23 percent.

In 2012, the federal level (Ministry of Health) committed R\$91.7 billion for the overall health budget. This represents the largest

⁷ Paim J, Travassos C, Almeida C, Bahia L, Macinko J. The Brazilian health system: history, advances, and challenges. *The Lancet*, Volume 377, Issue 9779, Pages 1778-1797, 21 May 2011

Solla J, Chioro A. Atenção ambulatorial especializada. In: Giovanella L, et al, organizadora. Políticas e sistema de saúde no

⁸ Brasil. Rio de Janeiro: Fiocruz; 2008: 627-73.

⁹ Ibid 7

¹⁰ Heiman L, Ibannes C, Barboza R. O public e o privado na saúde. Sao Paulo: Hucitec; 2005.

¹¹ Pan American Health Organization/WHO. Brazil health systems and services profile: monitoring and analysis of health systems change/reform, 2008. Brasilia, Pan American Health Organization/World Health Organization, 2011

¹² The World Bank. World Development Indicators 2010. <http://data.worldbank.org/country/brazil> (accessed February 10, 2012)

¹³ Ministerio da Saude. Orçamento para saúde tem seu maior aumento nominal

<http://portalsaude.saude.gov.br/portalsaude/noticia/4043/162/orcamento-para-saude-tem-%3Cbr%3Eseu-maior-aumento-nominal.html> (accessed March 12, 2012)

nominal increase for the sector since 2000, and a 17 percent increase since 2011¹³. Nearly half of these resources were transferred to states and municipalities¹⁴. The other half cover Ministry of Health expenses in its related entities (INCA, GHC, Fiocruz) and hospitals under direct Federal Ministry of Health administration.

Private financing comes from private entities and individual households. Private company expenditures are almost exclusively used to finance, typically on a partial basis, insurance or health plans for employees and dependents. Household expenditures for health are concentrated in the highest income brackets.

In 2010, the health expenditure in Brazil was 9 percent of GDP¹⁵. Public spending accounted for 46 percent and private expenditure accounted for 54 percent of health costs. In addition, a large proportion (57 percent) of private health expenditures is financed through out-of-pocket funds.

BREAST CANCER FINANCING

Adequate health care financing mechanisms are a key component of effective breast cancer control programs. This includes not only revenue collection mechanisms, but resource pooling and purchasing of services. The services needed for breast cancer control programs include: preventive services, early detection/screening, diagnosis (including pathology services), treatment (including surgery, radiotherapy, and systemic therapy) and palliative care (symptom management and end-of-life care).

Although some generalized cancer-specific data on health financing are available, data on breast cancer expenditures is not disaggregated, so it was impossible to obtain data and specific information on breast cancer-related spending. This lack of specific ways to capture data will handicap future efforts to track expenditures against result. On the other hand, as seen in the table below, increasing funding is being dedicated to cancer treatment overall by the federal public health system.

	1999	2009	2010
Oncological Surgery	87 million	173 million	173 million
Radiotherapy	77 million	164 million	210 million
Chemotherapy	306 million	1.2 billion	1.5 billion
Radioiodine	.05 million	4 million	5 million
Total	470	1.6 billion	1.86 billion

Table 1 Federal Spending (in Reais) on Oncological Services¹⁶

In May 2012, the federal government committed to investing an additional R\$ 505 million to strengthen radiotherapy services and buy equipment, including 80 linear accelerators to cover an additional estimated 29,000 patients.

More specific data on expenditures for cancer exists for Sao Paulo. The financing data below focuses on the provision of cancer services in the public health system of the municipality of Sao Paulo in 2007. In 2007, 25,989 hospitalizations with a primary diagnosis of cancer occurred among residents of Sao Paulo. This resulted financial value of R \$ 35 million paid to service providers. With regard to outpatient care, spending on chemotherapy totaled R \$ 73 million in 2007, while those related to radiotherapy

¹⁴ Ibid 11

¹⁵ Ibid 12

¹⁶ *Ministerio de Saude. Secretario Da Atencao A Saude – SAS. Seminario Direito A Saude. O O Cancer E A Oncologia No SUS. 2011*<http://www.portal.rn.gov.br/content/aplicacao/pge/arquivos/eventopgesus/oncologia%20no%20sus.pdf>

reached R\$ \$ 9.5 million.

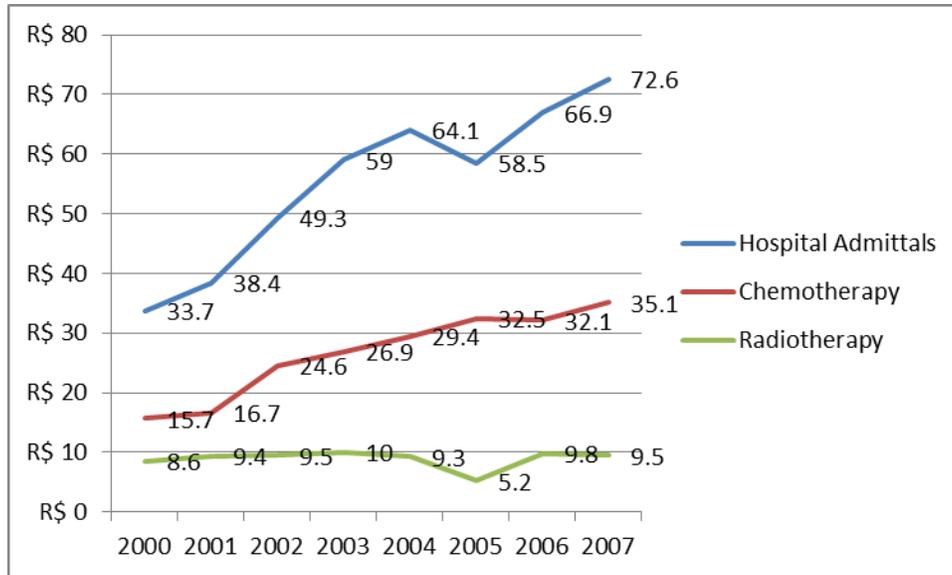


Figure 4 shows the evolution of spending on cancer care in the period between 2000 and 2007 in Sao Paulo (millions R\$).

Key informants interviewed during this assessment acknowledged the increasing investments, but they also identified challenges with the efficient transfer of funds between levels of the health system for cancer care. Those working at the main hospitals also identified challenges and frustrations with “justifying” additional budget based on demand for services. Budgets appear to be established on the basis of historic budget line items and, even when caseloads increase, additional budgets are not approved. This leaves all facilities having to treat more patients with the same resources. Finally, funding for equipment is approved through a special hospital equipment procurement process which respondents noted is long and extremely onerous.

Overall, however, respondents found that the financing system has improved in recent years, particularly since specialized services (such as mammography, radiotherapy, etc.) have been outsourced to third party providers. Funds are made available to reimburse these providers in a timely manner, based on a fees-for-service. Because these funds derive from a different budget line item than funds managed by the hospital, hospital administrators identified savings associated with outsourcing. In addition, they found the cost to have lowered through the contracting mechanisms because of economies of scale across the entire system.

Clearly, the gathering and compiling the financial information contained in the present report has been an arduous process. It points to the need for more investigation of the origin and final destination of the funds spent on cancer in Brazil, particularly disaggregating funding for breast cancer and other specific cancers.

IV. Breast Cancer Statistics and Burden of Disease

Worldwide, breast cancer is the most common cancer form in women; with an estimated 1.4 million new cases diagnosed each year. Breast cancer constitutes about one-fourth of all cancer cases in women and is the second most common cancer form overall.¹⁷

Incidence rates of breast cancer are significantly higher in developed countries than in developing countries. However, in developed countries, breast cancer mortality rates have declined in recent years, which is attributed to early detection through mammography and improved treatment.¹⁸

In contrast, in many newly-industrialized countries, incidence rates are increasing due to rapidly changing lifestyles reflecting those patterns in developed countries where we already see high incidence rate. At the same time, there is a steady increase in breast cancer mortality rates.

In Brazil, breast cancer is the leading cause of cancer mortality in women. It is the most common cancer in women in all regions except in the North, where cervical cancer ranks first. Brazil's breast cancer incidence is similar to that of high income countries. According to data from the Instituto Nacional de Cancer INCA (Brazilian National Cancer Institute), there will be an estimated 52,680 cases of breast cancer in Brazil in 2012.¹⁹ Approximately one third (30 percent) of all breast cancer cases occur in the State of Sao Paulo. Sao Paulo City alone will need to respond to approximately 6,000 new cancer cases in 2012.²⁰

The age-adjusted mortality rate for breast cancer is on an upward trajectory. It is the leading cause of cancer death in Brazilian women, with 11.3 deaths/100 thousand women in 2009.²¹ The Southeast and South regions have the highest rates, with 12.6 and 12.7 deaths/100 thousand women in 2009, respectively.

Sao Paulo City's breast cancer mortality rate is significantly higher than the national average (Figure 1)²².

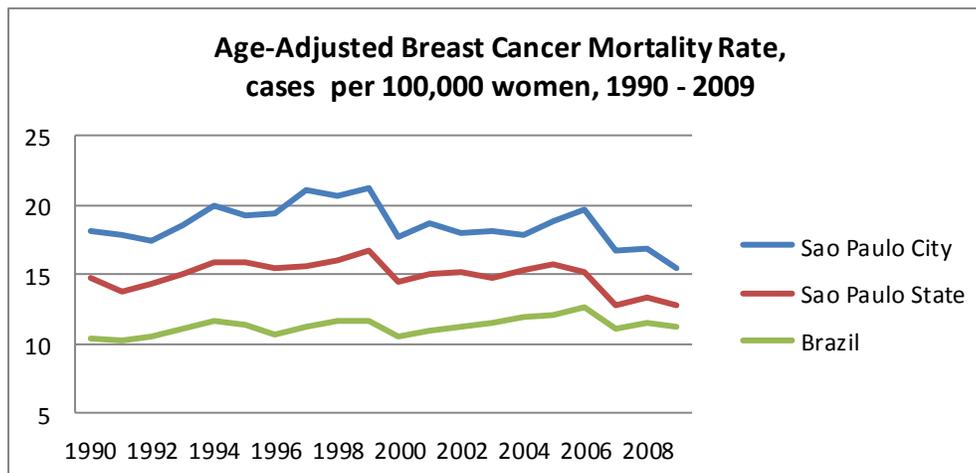


Figure 1. Breast Cancer Mortality Rate since the 1990s

¹⁷American Cancer Society. *Global Cancer Facts and Figures*. 2nd Edition.2008

¹⁸Althuis MD, Dozier JD, WF A, et al. *Global trends in breast cancer incidence and mortality 1973-1997*. *Int J Epidemiol*. 2005;34:405-412.

¹⁹Instituto Nacional do Cancer, Ministério da Saude. *Estimativa 2012 Incidencia de Cancer no Brazil*. *Cancer de mama feminina*. <http://www.inca.gov.br/estimativa/2012/index.asp?ID=5> (accessed March 1, 2012)

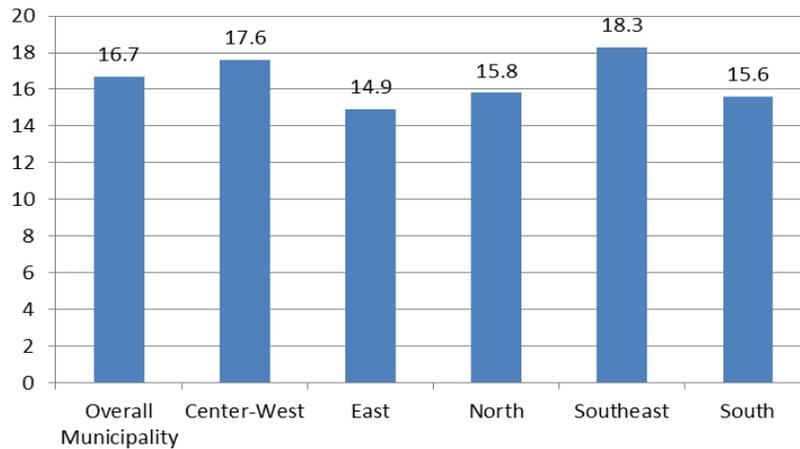
²⁰Instituto Nacional do Cancer, Ministério da Saude. *Estimativa 2012 Incidencia de Cancer no Brazil* <http://www.inca.gov.br/estimativa/2012/tabelaestados.asp?UF=BR> (accessed March 1, 2012)

²¹Instituto Nacional do Cancer, Ministério da Saude. 2009. *Atlas de mortalidade por cancer: taxas de mortalidade por cancer de mama, por 100 000 mulheres*. <http://mortalidade.inca.gov.br/Mortalidade/prepararModelo05.action> (accessed March 2, 2012)

²²Instituto Nacional do Cancer, Ministério da Saude. 2009. *Atlas de mortalidade por cancer: taxas de mortalidade por cancer de mama, por 100 000 mulheres* <http://mortalidade.inca.gov.br/Mortalidade/prepararModelo07.action> (accessed March 9, 2012)

Figure 2 illustrates breast cancer mortality in Sao Paulo municipality, disaggregated by sub-region. The Center-West and Southeast regions have the highest number of breast cancer deaths followed by the Northern region. An analysis of mortality rates by sub-region suggests that regional inequalities deserve more study.

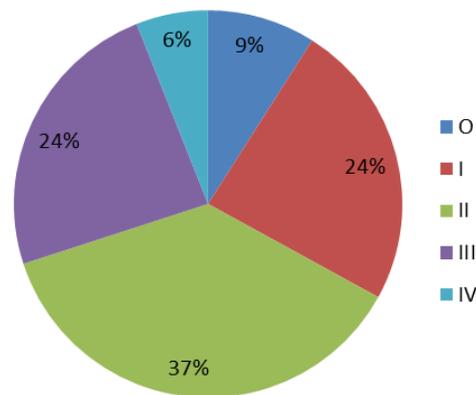
Age- Adjusted Breast Cancer Mortality Rates per 100,000 in Sao Paulo Municipality, by Region²³



As in most developed countries, the large majority of breast cancer cases are diagnosed at age 50 and over.²⁴ Recent studies reported that 20-2% of patients in Brazil were diagnosed with stage I breast cancer; 46-8% had stage II; 24-6% had stage III; and 5-5% had stage IV disease²⁵. Similarly, breast cancer stage at diagnosis data provided by the Sao Paulo's Hospital Cancer Registry and managed by the Oncocentro Foundation of Sao Paulo (FOSP), shows that one third of breast cancer cases in Sao Paulo are diagnosed at late stages. Five-year survival rates for patients with breast cancer are low when compared with those of high-income countries²⁶. This low survival can be explained by late presentation of the disease, which, when coupled with limited resources for diagnosis and treatment, leads to poor outcomes.

Because much can be done to increase survival and improve quality of life when breast cancer is diagnosed early, addressing high mortality rates and late-stage diagnosis should be a key target in any comprehensive strategy to address breast cancer.

Figure 3 Disease Stage at Diagnosis, Municipality of Sao Paulo, 2007²⁷



²³ Sao Paulo (SP). Secretaria Municipal da Saúde. Coordenação de Epidemiologia e Informação – CEInfo. Boletim CEInfo Análise nº 3, 2009: Impacto do câncer no Município de Sao Paulo, Sao Paulo: CEInfo, 2009, 32 p.

²⁴ Ibid 23

²⁵ Simon SD, Bines J, Barrios CH, et al. Clinical characteristics and outcome of treatment of Brazilian women with breast cancer treated at public and private institutions—the AMAZONE project of the Brazilian breast cancer study group (GBECAM). San Antonio Breast Cancer Symposium 2009; San Antonio, TX, USA; Dec 11, 2009. Abstr 3082.

²⁶ Coleman MP, Quaresma M, Berrino F, et al. Cancer survival in five continents: a worldwide population-based study (CONCORD). Lancet Oncol 2008; 9: 730–56.

²⁷ Sao Paulo (SP). Secretaria Municipal da Saúde. Coordenação de Epidemiologia e Informação – CEInfo. Boletim CEInfo Análise nº 3, 2009: Impacto do câncer no Município de Sao Paulo, Sao Paulo: CEInfo, 2009, 32 p.

V. Organization of Breast Health Service Delivery

BREAST CANCER CARE NETWORK

Cancer care through SUS is organized through state or regional referral centers that are responsible for providing diagnosis, staging, and treatment. National Oncological Care is defined and proscribed by federal law. Current standards are based on 2439 GM ordinances and SAS 741 (2005). These standards state that National Oncological Care must be organized in coordination between the Ministry of Health and Health Departments of the states and municipalities and include range of care at all levels - basic, specialized care (secondary and tertiary care), and promotion, prevention, diagnosis, treatment, rehabilitation and palliative care.

High complexity services (or tertiary cancer care) are provided through High Complexity Units in Oncology (UNACON), High Complexity Centers in Oncology (CACON) and Hospitals with General Surgical Oncology, and occasionally isolated chemotherapy and / or radiotherapy services.

Table 1 shows the relationship of the institutions of Sao Paulo Municipality accredited for cancer care in the SUS. As can be observed, the vast majority of services are under state management.

Institution	Type of Facility	Administration
Women's Health Reference	UNACON	State
Mandaqui Hospital Complex	General Hospital	State
A.C.Camargo Hospital	CACON with Pediatrics	Municipal
Brigadeiro Hospital	UNACON with Hematology	State
University of Sao Paulo Clinical	CACON with Pediatrics	State
Vila Nova Cachoeirinha General	General Hospital	State
Heliópolis Hospital	UNACON	State
Hospital Darcy Vargas Children's	UNACON exclusive for Pediatrics	State
Ipiranga Hospital	UNACON	State
Santa Marcelina	CACON with Pediatrics	State
Sao Paulo Hospital		
Inst. Brasileiro de Contro-le do Câncer - IBCC		
Arnaldo V. Carvalho Cancer Institute	CACON	Municipal
State Cancer Institue Sao Paolo	UNACON with Hematology	State
Santa Casa of Sao Paulo Hospital	UNACON com Hematologia e Pediatria	State
Portuguese Beneficent Society	CACON com Pediatria	Municipal

Table 1: List of Accredited Institutions for Cancer Care Health System in the Municipality of Sao Paulo

Basic breast healthcare services (orientation, education, clinical breast exam, and screening mammography) are available at primary and secondary level facilities located in all zones of the city. Medium complexity units (or secondary level facilities) provide a referral mechanism for women with abnormal mammograms. This level has specialists to perform the diagnostic investigation of suspected cases of breast cancer, including diagnostic mammography, fine needle or core needle biopsy, and treatment of the

benign breast conditions. Few of these facilities rely on pathology laboratories of their own or typically, refer to an outside laboratory if one is not available at the facility.

Key informants report that, although available, secondary level facilities do not always cover demand in a timely manner. There are waiting lines for breast cancer diagnostic services and long lines required to obtain appointments. Most respondents (80%) identified reasons for delays occurring at the secondary level as being due to lack of organization in the referral system, fragmentation of services and a lack of capable staff to adequately complete the diagnosis process. The median lapse time between mammography and diagnosis, reported by respondents, is between 60-120 days. Sometimes it can take even longer, so a woman must wait more than six months before receiving a definitive diagnosis and treatment. Thus, often times women who can afford choose to refer private sector for more expedite diagnostic services.

Referrals are coordinated by the central oncological regulatory referral body at the municipal level, based on available vacancies/appointments. Nevertheless, in practice, health care professionals at UBSs often opt to refer to their facility of choice or patients themselves self-direct to tertiary level facilities where they know they will not be turned away. This produces a skewed system of referrals because UBS health care providers are not able to reassure women about her diagnosis without specialist assessment. As a result of delays and frustration, an increasing number of women are being referred to cancer referral centers, bypassing secondary level specialized facilities, so the benign to malignant ratio is rising. The result is that some facilities being over utilized and others are underutilized. Most informants interviewed identified a breakdown in the referral system due to ineffective organization of the referral clinical network, weak enforcement of the referral chain and lack of coordination for breast cancer care clients.

Tertiary facilities are less ubiquitous and women often must travel to other parts of the city to receive tertiary level services (diagnosis, surgery, treatment). Facilities that provide the full range services (i.e. from education => screening => diagnosis => treatment => follow-up care) in one place are very limited. For instance, even the most advanced, specialized tertiary facilities in the public sector refer patients to private clinics or hospitals contracted by the SUS for provision of radiotherapy and/or chemotherapy services.

In addition to lack of coordination of medical services at service sites, the full range of services is not available in a geographically and medically balanced way. The distribution of breast health services is biased toward wealthier areas of the city, with the lack of services in outskirts of the city and poor areas. Informants reported that many women drop out of system because of a lack of access to higher level services near their residence.

In sum, although there is a full range of services available for breast cancer diagnosis and treatment, complexity of organization, a sub-optimally functioning referral system, and distribution of services presents patients and providers alike with challenges in providing and receiving optimal and timely care.

MAMMOGRAPHY SCREENING AND EARLY DIAGNOSIS

The Ministry of Health of Brazil's national guidelines recommend mammography screening every two years for women aged 50–69 years and every year starting at 35 years of age for women with a family history of breast cancer. Although screening guidelines were published in 2004, specific legislation was enacted only in 2008 to ensure access to mammography²⁸.

In 2005, with the launch of the National Oncological Care Program²⁹, breast and cervical cancer control were highlighted as key components of state and municipal health plans. In the same year, the Breast and Cervical Cancer Control Plan was drafted, which

²⁸ Instituto Nacional de Câncer. *Controle do câncer de mama: documento de consenso*. Rio de Janeiro, Brazil: Ministério da Saúde, 2004

²⁹ Ministerio de Saude. *National Policy for Oncological Care – Ministerial Resolution PT/GM GM nº 2439, December 8, 2005*. http://www.saude.mg.gov.br/atos_normativos/legislacao-sanitaria/estabelecimentos-de-saude/oncologia/Portaria2439.pdf

proposed six strategic objectives:

- increased coverage for target populations,
- quality assurance,
- strengthening the information system,
- developing a capabilities strategy,
- social mobilization, and
- developing research.

In 2009, the National Cancer Institute (INCA) which coordinates cancer policies on a national level (with participation of National Ministry of Health and State Health Secretaries) developed National Program for Breast Cancer Early Detection providing recommendations for implementation of a population-based breast cancer national screening program. As a result of these and other efforts to improve breast cancer control in recent years, in 2009, the Ministry of Health implemented SISMAMA – Breast Cancer Information System. This system requires every government facility, contracted private imaging center or pathology laboratory to provide certain standardized information that is recorded in SISMAMA prior to reimbursement. The supply of mammograms and also the availability of information about screening in the population increased. INCA published several key documents, including guidelines and technical parameters for breast cancer screening in Brazil.

The municipality of Sao Paulo follows recommendations for breast cancer screening defined by INCA and the Ministry of Health. Clinical breast exams are given annually to women over 40 years and a mammogram is performed every two years for women between 50-69 years, except for the higher risk groups. Current screening modality in Sao Paulo municipality can be described as opportunistic, depending on women presenting for this service rather than outreach or other systematic ways of reaching women clients.

Recent data from the 2008 ISA Capital, a health survey conducted through an agreement between the Municipal Health Secretariat of Sao Paulo and School of Public Health of the University of Sao Paulo showed that 74.3% of women between 50 and 69 years had undergone mammography screening in the last two years. Although the data suggest increase in mammography use, the diagnosis of breast cancer is being made in later stages, suggesting the possible existence of problems in the process of tracking of the women with abnormal mammograms. In addition, although one-time and recent mammography use improved, all respondents interviewed identified low adherence to guidelines regarding repeat mammography.

The data obtained from the Information System of SUS/DATASUS of the Ministry of Health showed that in 2011 there were 290 666 screening bilateral mammograms conducted through the public system in Sao Paulo. Out of 238 mammography machines total in the health establishments in Sao Paulo Municipality, there are 60 machines (25%) available in the SUS public system³⁰. However, there was no data or information available on functionality of these machines or output per center with a functioning machine.

Map 1 identifies the distribution and location of public facilities (state and municipal) providing mammography services and shows the areas of social deprivation. The social deprivation is an important measure in order to identify areas of deprivation and to target women who live in such areas, and locate services appropriately. Women living in socially deprived areas are more likely to experience poor access to information, support and services.

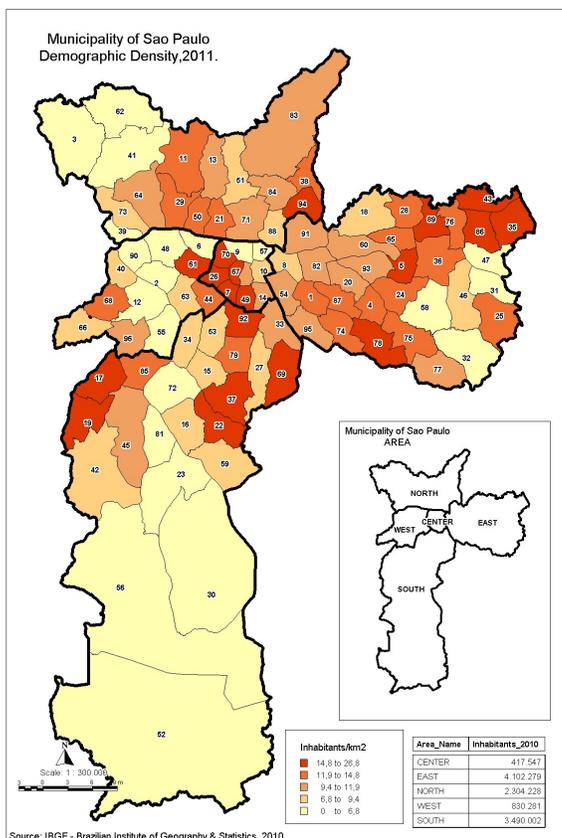
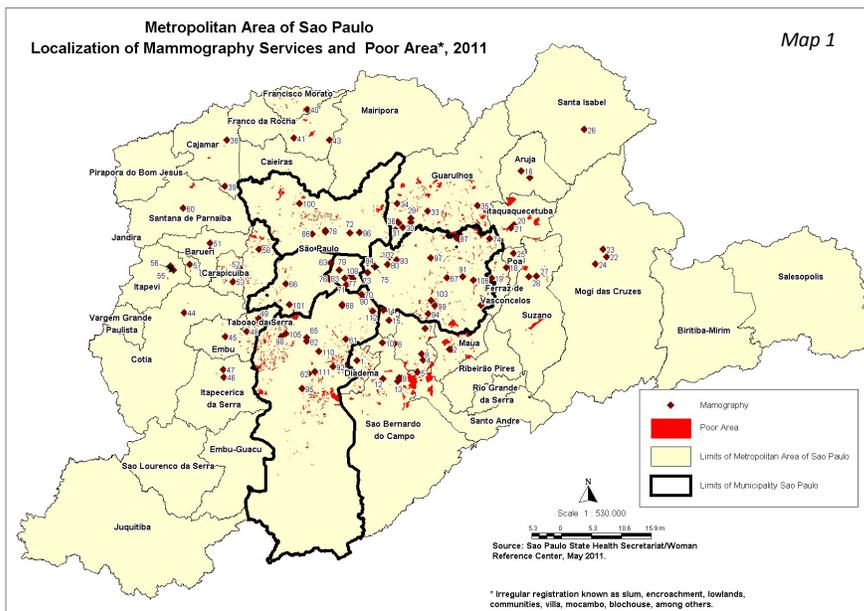
Socially deprived areas are clustered in the North Zone, in *Perus, Piritubi-Javaqua, Frequesia-Brazilandia, Casa-Verde and Jacana-Tremember* sub-prefectures. The East Zone also incorporates multiple deprived areas with higher concentration in *Sao Miquel*

³⁰ Instituto Brasileiro de Geografia e Estatística, Diretoria de Pesquisas, Coordenação de População e Indicadores Sociais, Pesquisa de Assistência Médico-Sanitária 2009.

Paulista and Sao Mateus sub-prefectures and areas on the border with Guarhuous and Maua regions. High levels of deprivation can also be found in the South Zone. As evident by this mapping exercise, the areas are located in Capelado Socorro, Cidade Ademar, Mboi Mirim and Cambo-Limpo sub-prefectures.

When analyzing mammography services, it is evident that large proportion of facilities offering mammography services is concentrated in the Central Zone of Sao Paulo municipality. This area hosts multiple public and private tertiary hospitals, cancer centers, clinics and diagnostic centers. The large proportion of Sao Paulo Municipality's screening mammography is conducted in the Central Zone. Some of the public and charity hospitals and clinics with the highest volume of screening mammography services in this area include State Referral Center for Women called also Perola Byington Hospital (13,923), Hospital Das Clinicas Da FMUSP (11,984), Ambulatorio Penha-Maurice Pate (11,926), and Santa Casa De Sao Paulo Hospital Central (8,942). There is also number of public facilities in this area providing on average 5,000 screening mammograms per year.

The East Zone has the largest population and density (Map 2). There are several specialized ambulatories and UBS with high volume screening mammography. The East Zone public hospitals, Santa Marcelina De Itaim Paulista and Santa Marcelina perform on average 5,000 screening mammograms annually. Uneven spread of mammography facilities in the East Zone suggests unequal access to screening mammography in certain districts.



As it is evident from the map, the North and South Zones, which also contain multiple deprived areas, has few facilities with mammography services. In the North Zone, the mammography services with the volume on average of about 8,500 screening mammograms per year are concentrated in three facilities - Vila Nova Cachoeirinha Hospital, Municipality Hospital Cachoeirinha-Mario De Moraes A Silva and the specialized secondary level facility – Ambulatorio Especialidades Tucuruvi-Armando De Aguiar Pupo. Further, towards the north in this area there is the UBS Uniao Das Vilas De Taipas, which provides over 7,000 screening mammograms per year. The population level and density and the number and distribution of mammography facilities in this zone, suggests potential issues with access to mammography services.

The South Zone is also lacking mammography services, but here the population density is relatively low, particularly further in the south, so there may not be as great a need for a concentration of services in this area. Facilities with high volume of screening mammography in the South Zone include municipality hospitals, Campo Limpo (17,419) and Santa Casa De Santo Amaro (9,674), State Maternity Hospital Interlagos (8,298) and several specialized municipal ambulatories providing from 4,000 to 10,000 screening mammograms annually.

Map 2

Population density and number of people leaving in the West Zone is relatively low (Map 2). There are two public facilities with mammography services – state run Hospital Sao Paulo UNIDADE I and municipality UBS V SONIA with 2,520 and 3,074 screening mammography conducted in 2011, respectively. It is arguable whether it is cost effective to locate face-to-face services in this area, when the number of clients will be small. It would be prudent to consider alternative modes of service delivery in sparsely populated areas.

Only mobile mammography model is planned to be implemented by the Hospital Oswaldo Cruz, a private hospital offering community services in the neighborhood of Mooca, east of Sao Paulo, in collaboration with the non-profit association Institute Se Toque. Mobile Program Unit model could perhaps be a model to build upon to improve an access to the mammography services, especially in sparsely populated areas and areas with lack of mammography services, albeit on a transient, not permanent, basis.

Pathology and surgery service capacity can also be barriers to care. The choice of tissue sampling techniques (FNAC, core biopsy, or surgical biopsy) largely depends on local availability of equipment, expertise and costs. Biopsy, fine needle cytology or a core biopsy, is performed in few large tertiary hospitals and specialized secondary level facilities. Several respondents identified significant delays with pathology reporting (90 days, average) and lack of financing for replacement supplies and equipment.

This mapping exercise has highlighted some important potential issues for access to mammography and early diagnosis services to consider, particularly as the mammography screening program intends to reach more people. By producing maps of the location of mammography services, it is evident that there is consistent provision of services in some areas, and a lack of provision in others. However, it should be acknowledged that limitations exist with regard to the datasets and information used in this mapping exercise. Data on services provided in private sector hospitals and clinics are lacking impeded due to availability of resources and time required for data collection. In addition, it is unknown to what extent women from low-resourced or socially disadvantaged areas of the city are willing and able to travel to the central part of the city to achieve routine breast health care. Willingness to do this may depend on funding to defray transportation costs, excess capacity at central facilities, willingness to see women from other parts of the city and—critically—knowledge and awareness of clients, particularly poor clients, of the importance of having regular mammograms.

It is important to build on this mapping exercise, by investigating breast cancer incidence, population size, ethnicity and deprivation, breast health care services at specific geographic areas and zones, to identify specific areas of demand/unmet need among local communities. This will further help to inform breast health services and program planning, strategy development, and development of public education programs about the importance of breast health care. A detailed cost-benefit, capacity and efficiency analysis should be also undertaken, which takes account of varying population densities, to assist in the planning of future service locations or determining alternative service delivery strategies.

BREAST CANCER TREATMENT

Breast cancer surgeries are mainly conducted at cancer specialized tertiary level and reference hospitals of Sao Paulo Municipality. Although, some of the breast cancer surgeries are being performed in non-specialized facilities (i.e. maternity hospitals), for systemic and radiotherapy treatment women are referred to high complexity cancer units and centers or private hospitals. Surgical procedures identified by respondents include breast-conserving surgery, mastectomy, and axillary lymph node removal. A sentinel lymph node biopsy has been also identified by respondents as a procedure done in most specialized cancer centers. Our assessment did not collect information or analyze quality of surgery and differences between surgical procedures in facilities visited.

The provision of a high quality radiation oncology service is one of the cornerstones of any modern treatment program for cancer patients. In Sao Paulo, radiotherapy services are provided by specialized cancer centers and radiotherapy facilities, and general hospitals. Linear accelerators and cobalt machines are used. The number of radiation units in Sao Paulo (6.01 per million

population) is higher than the national average (0.93 per million population).³¹ However, availability alone does not determine access to radiotherapy. Geographical accessibility and affordability by patients and their families to cover the cost related with travel and other indirect costs associated with treatment can be barriers to access to radiation therapy.

The development of radiotherapy treatment services has been identified as an important priority by the federal government. In 2012, Ministry of Health announced that it will invest in purchasing additional radiotherapy units.

For patients with hormone-receptor positive tumors, tamoxifen is widely available in Brazil for adjuvant therapy, independent of women's menopausal status. Tamoxifen used as the first line treatment and the prescription of aromatase inhibitors is usually restricted to patients with tamoxifen intolerance.

Substantial differences exist in regimens used for adjuvant chemotherapy. More than half the patients treated in public institutions receive first-generation regimens, such as cyclophosphamide, methotrexate and fluorouracil (CMF) or doxorubicin and cyclophosphamide, compared with less than a third of patients treated in private institutions³². Key respondents said that the standard approach in their institutions is anthracycline-based chemotherapy. Anthracycline-based chemotherapy is preferred over CMF chemotherapy based on indirect evidence from studies of women with axillary node-positive breast cancer or metastatic disease³³.

Access to anti-HER2 therapy is very restricted in the public health system. The public system usually does not reimburse modern drugs such as trastuzumab, mostly because it is cost-prohibitive for the public health system. High cost has largely precluded its adoption as a standard. Recently, increasing clinical trial activity in oncology can be the only way to get an access to modern and new drugs and potentially effective treatment. Sao Paulo is an exception to this, because of the State's recent decision and Act called "APAC" Paulista. The "APAC" Paulista provides list of exceptional medicines, including trastuzumab that Sao Paulo State is required to reimburse³⁴.

PALLIATIVE CARE

For advanced cancer, health systems need to offer palliative care to alleviate pain and unnecessary morbidity. WHO recommends that every country offer a comprehensive national palliative-care program. The documents consulted list palliative care as an important component of cancer control program; however, they do not provide recommendations or actions required for setting up hospice or palliative care services and/or programs. Most interviewees (80%) responded that palliative care only offered by oncology units, and medical oncologists are the ones who provide care to patients diagnosed with metastatic diseases until the end.

³¹ International Atomic Energy Agency. *Directory of radiotherapy centers by country and region*. <http://www-naweb.iaea.org/nahu/dirac/query.asp> (accessed April 20, 2012)

³² Simon SD, Bines J, Barrios CH, et al. *Clinical characteristics and outcome of treatment of Brazilian women with breast cancer treated at public and private institutions—the AMAZONE project of the Brazilian breast cancer study group (GBECAM)*. *San Antonio Breast Cancer Symposium 2009; San Antonio, TX, USA; Dec 11, 2009*. Abstr 3082.

³³ Alexandru Eniu et al. *Breast Cancer in Limited Resource Settings: Treatment and Allocation of Resources*. *Breast Health Global Initiative. The Breast Journal, Volume 12 Suppl. 1, 2006 S38–S53*

³⁴ Personal communication: Lucian Holtz, President, Institute of Oncogua, Sao Paulo, 2012.

VI. Cancer Registry

Cancer registries are systems of information specific to a particular disease; they play an important role in cancer epidemiology. This report not meant to provide an assessment of cancer registry or to evaluate data quality in the registry. On the other hand, information collected through interviews and documents consulted helped to get a general understanding of cancer information collection in Sao Paulo. Sao Paulo has two registries, the Population –Based Cancer Registry (PBCR) and Cancer Hospital Registry (CHR), which is assigned to the Oncocentro Foundation of Sao Paulo (FOSP). Currently, 75 hospitals submit information to the state CHR, which records data about patients, tumors and provided treatment. The CHR is linked to PBCR, which gathers data on incidence and mortality statistics. The data reported by the state PBCR are not age-standardized. INCA uses these data to estimate the number of new cases expected for the following year and publishes age-standardized mortality rates.

Over 60% of respondents questioned the data completeness and quality of CHR. In addition, the limited use of cancer registry data has been observed by health care professionals. The respondents also identified the lack of federal funding for PBCR.

Limited information collected from the interviews with policy-makers and health providers suggest that Sao Paulo cancer registry warrants more detail review for degree of its completeness, data quality and timeliness. Reporting mechanisms and procedures, including registration routines and quality control procedures also need to be looked to evaluate the quality of cancer registry and develop the policies and measures for improving the registry.

VII. Conclusions and Recommendations

Brazil in general and Sao Paulo City specifically have made remarkable progress in addressing breast cancer, a major killer of their women. Their resolve and commitment cannot be faulted. National, State and Municipal policies and practices have been informed by the best available international evidence, as well as by local research and a superb cadre of medical/clinical professionals. Brazil has a large public and private health infrastructure and decentralized system it can draw on to attack breast cancer. Both public and private resources for breast cancer are increasing as well as awareness among the general population, the result of breast health public awareness activities conducted by the public sector and private sector and dynamic NGO community.

Despite enormous gains to date, many challenges persist. Breast cancer is still being diagnosed too frequently in late stages. Growing demand for services is not being adequately met. The infrastructures and systems for addressing each stage of breast cancer, from early diagnosis through late stages, appear to be complex and hard for clients to negotiate. Mapping data suggest persistent inequities in access to services and other data suggest ongoing need for public education for compliance with standards. All of these challenges are surmountable, particularly within the context of high political, medical and social value Brazil places on breast health and addressing breast cancer. It is thus in the spirit of careful examination of issues leading to even better strategies for improvement by activists and public and private health leaders and the Susan G. Koman for the Cure that recommendations in this report are made. Some recommendations overlap, or provide more specific ideas for future strategies or possible programmatic improvements.

Recommendation #1: Study and address (incentives, location of facilities, public education) potential geographic and socio-economic inequities in service delivery access in specific areas and sub-populations of Sao Paulo City

Sao Paulo already has a considerable number of mammography facilities. The information collected and the findings suggest that any problems with mammography access are localized in nature rather than widespread. On the other hand, some issues in distribution and access to mammography and early diagnosis services in certain geographic zones became evident. There appears to be a consistent provision of services in some areas, and a lack of provision in others. Thus there is a need to use this broad picture to hone down on zones and sub-prefectures to scrutinize/explore further breast cancer incidence broken down by districts, population density, ethnicity and deprivation of local areas to fully understand the breast cancer population in specific localities of interest, and their need for breast health care information, support and services.

Recommendation #2: Study and strategize to address fragmentation of services, particularly needed improvements to the referral system and increase patient-oriented and focused care.

A fragmentation of services, lack of continuity, inadequate referral system and lack of a coordinated plan for breast healthcare at the state and municipal level became evident through this assessment. Huge challenges face the current organization of breast health care system, particularly elimination of long waiting lists (and times) for specialized ambulatory care and diagnostic services. These waiting times translate directly into increased morbidity and mortality.

Having waited for referral, the results of a diagnosis and treatment to be initiated results in patient high drop-out from the continuum of care. The development of a clinical network of breast cancer diagnosis and treatment centers that will establish appropriate outreach services to UBS, secondary level facilities and other hospitals in a partnership model has a potential to improve the continuity of care and coordination of breast health care.

Recommendation #3: Provide technical assistance and support to the FOSP's technical committee in developing effective policies and reorganizing referral systems.

Under the leadership of the Oncocentro Foundation of Sao Paulo (FOSP), the State recently convened a technical committee to evaluate and develop the referral system for breast and cervical cancer. The technical committee is comprised of FOSP, Cancer Institute, Sao Paulo University Hospital, experts in breast and cervical cancer and State Health Secretary. Technical assistance and

support to this technical group will be of paramount importance for developing of effective policies and re-organization of referral system and implementation of changes.

Recommendation #4: Explore development of “One-stop” breast health clinics.

Attempts have been also made to implement patient-focused care and to minimize the delays through the development of so called “one-stop” diagnostic services (i.e. Perola Byington Hospital). “One-stop” diagnostic services provide reliable and accurate ways of establishing a rapid diagnosis and minimize delays. For this model to be effective and safe, it is necessary to conduct analyses of capacity of health care facilities, particularly specialized ambulatories and secondary level facilities, to provide a sound basis to implement this model.

Recommendation #5: Expand patient navigation systems.

The evidence is growing for the effectiveness of patient navigation interventions in reducing disparities in cancer treatment. Patient navigation program and specific activities such as case identification, detection of individual barriers to care, care plan implementations, and tracking through treatment completion can increase case follow-up rates and diagnosis after abnormal mammogram and improve treatment outcomes. Patient Navigation Program implemented by the Institute of Oncogua through Brazil Global Initiative funded by the Susan G. Komen Breast Cancer Foundation shows first results in improving patients experiences in breast cancer care.

Patient navigation is an initiative that can be further supported and expanded through development of a breast cancer navigation workgroup to share resources, best practices and suggestions for system improvements.

Recommendation #6: Empower FHTs and UBS to become more proactive in community education and facilitation diagnostic and care services throughout the cycle of the disease.

Despite the important growth and improvement of family health program and primary health care in the last few years, major gaps remain in primary care provision for breast health care.

Empowering the Family Health Teams and Unidades Basicas de Saúde- UBS (Basic Health Units), especially in areas of social deprivation and sparsely populated, through building the capacity of these primary health care assistance units in provision of breast health information, facilitating access to mammography screening and breast cancer diagnostic services, actively searching and providing follow-up of women with abnormal mammograms and breast cancer diagnosed women, and serving as a more responsive channel between community and healthcare units should be supported. Training of health care providers on standard breast health care guidelines by level of care and protocols and referral processes should be prioritized.

Recommendation #7: Continue and expand public awareness and community involvement activities in breast cancer through a variety of mechanisms.

The Ministry of Health, Sao Paulo State and municipality health authorities, and local non-governmental organizations (through support from Brazil Global Initiative for Breast Cancer Awareness funded by Susan G. Komen for the Cure and other local and international initiatives) have already initiated efforts to improve early diagnosis and promote breast cancer screening through education and public awareness activities.

Breast cancer public awareness activities need to be continued and expanded. Targeted efforts, using alternative modes of information delivery, such as cell phones, twitter or web-based information and support, can reach out more broadly to meet the needs of people living in sparsely populated areas and poor communities.

Recommendation #8: Increase use breast cancer data from registries and other information systems for decision making

The cancer registry and other national information systems provide a wealth of data on services available throughout the health system. These data are particularly robust in Sao Paulo state and city. However, these systems are difficult to navigate and extract

information in a user-friendly fashion. Furthermore, several respondents acknowledged that these systems exist but expressed challenges finding the time to extract the data to use for decision-making.

Further investment should be made to summarize and present the available data to policymakers. In addition more use friendly portals and informational systems to more easily extract data and generate interactive reports and graphs on the basis of these extensive information systems. These complementary systems could help improve communication among programs and ensure policymakers and managers have and understand the data they need to make decisions.

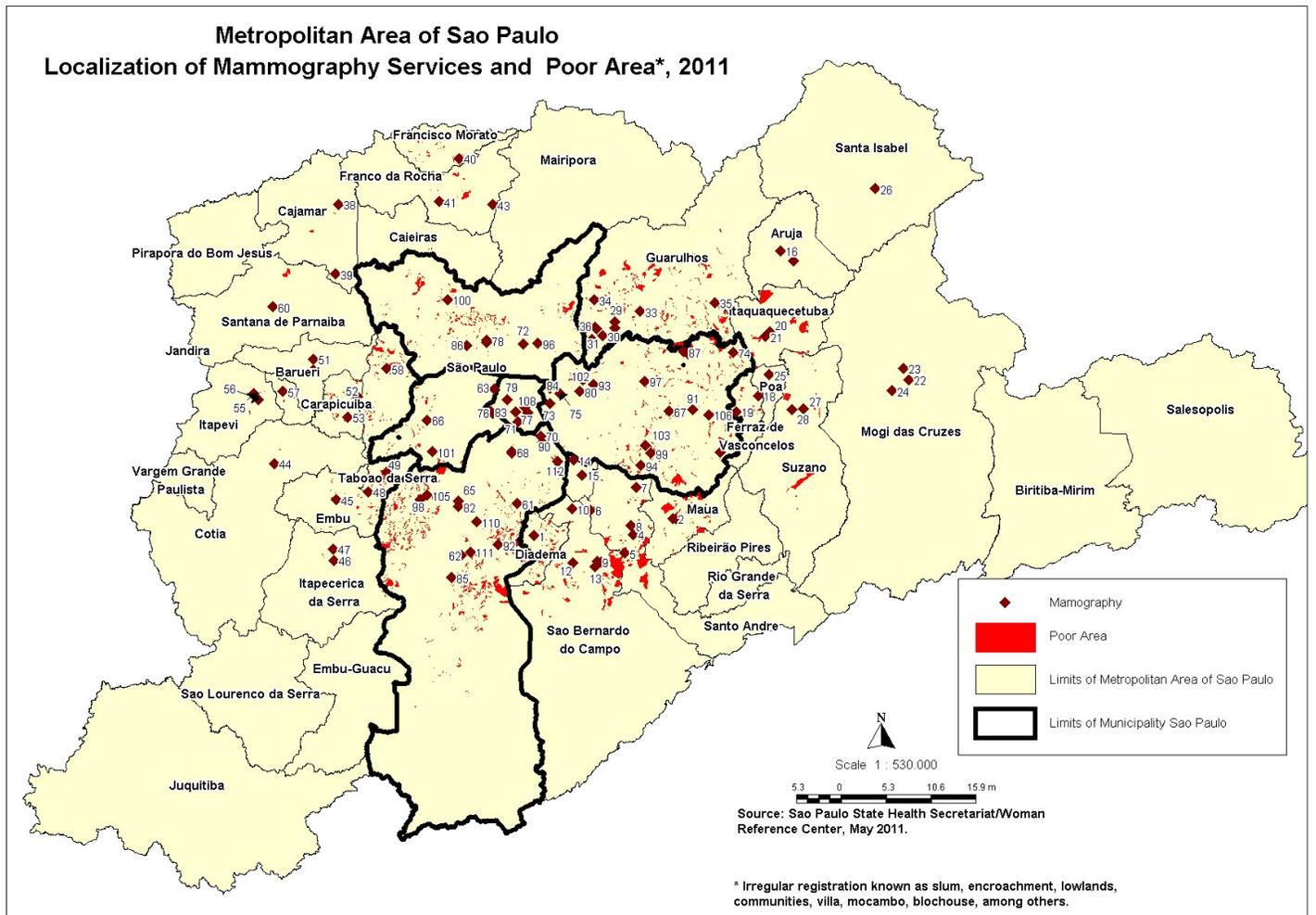
To summarize, Brazil and the city of Sao Paulo are to be commended both for medical-technical achievements in breast cancer diagnosis and treatment and for their commitment to doing even more. The significant challenges that exist in reducing breast cancer morbidity and mortality and achieving client-centered care are surmountable.

REFERENCES

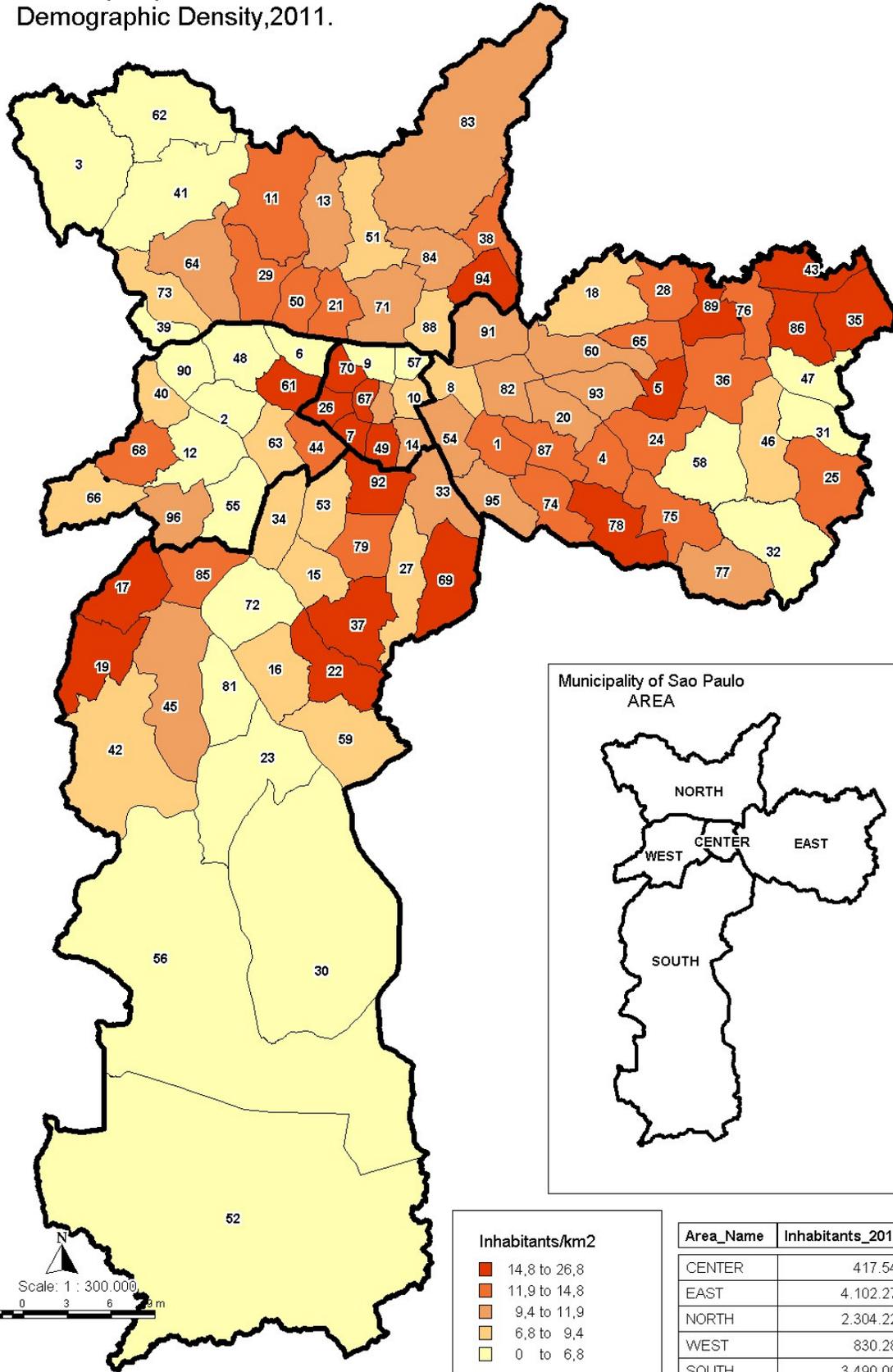
- Maria Inês Schmidt et al. Chronic non-communicable diseases in Brazil: burden and current challenges. *The Lancet*, Volume 377, Issue 9781, Pages 1949 - 1961, 4 June 2011
- Instituto Brasileiro de Geografia e Estatística. http://www.ibge.gov.br/home/presidencia/noticias/noticia_visualiza.php?id_noticia=1866&id_pagina=1 (accessed February 14, 2012)
- The World Bank. World Development Indicators, <http://data.worldbank.org/country/brazil> (accessed February 10, 2012)
- Paim J, Travassos C, Almeida C, Bahia L, Macinko J. The Brazilian health system: history, advances, and challenges. *The Lancet*, Volume 377, Issue 9779, Pages 1778 - 1797, 21 May 2011
- Instituto Brasileiro de Geografia e Estatística. 2010 Population Census. <http://www.ibge.gov.br/english/estatistica/populacao/censo2010/default.shtm> (accessed March 12, 2012)
- Solla J, Chioro A. Atenção ambulatorial especializada. In: Giovanella L, et al, organizadora. Políticas e sistema de saúde no Brasil. Rio de Janeiro: Fiocruz; 2008: 627–73.
- Heiman L, Ibannes C, Barboza R. O público e o privado na saúde. São Paulo: Hucitec; 2005.
- Pan American Health Organization/WHO. Brazil health systems and services profile: monitoring and analysis of health systems change/reform, 2008. Brasília, Pan American Health Organization/World Health Organization, 2011
- American Cancer Society. Global Cancer Facts and Figures. 2nd Edition. 2008
- Althuis MD, Dozier JD, WF A, et al. Global trends in breast cancer incidence and mortality 1973-1997. *Int J Epidemiol*. 2005;34:405-412.
- Instituto Nacional do Câncer, Ministério da Saúde. Estimativa 2012 Incidência de Câncer no Brasil. Câncer de mama feminina. <http://www.inca.gov.br/estimativa/2012/index.asp?ID=5> (accessed March 1, 2012)
- Instituto Nacional do Câncer, Ministério da Saúde. Estimativa 2012 Incidência de Câncer no Brasil <http://www.inca.gov.br/estimativa/2012/tabelaestados.asp?UF=BR> (accessed March 1, 2012)
- Instituto Nacional do Câncer, Ministério da Saúde. 2009. Atlas de mortalidade por câncer: taxas de mortalidade por câncer de mama, por 100 000 mulheres. <http://mortalidade.inca.gov.br/Mortalidade/prepararModelo05.action> (accessed March 2, 2012)
- Instituto Nacional do Câncer, Ministério da Saúde. 2009. Atlas de mortalidade por câncer: taxas de mortalidade por câncer de mama, por 100 000 mulheres. <http://mortalidade.inca.gov.br/Mortalidade/prepararModelo07.action> (accessed March 9, 2012)
- São Paulo (SP). Secretaria Municipal da Saúde. Coordenação de Epidemiologia e Informação – CEInfo. Boletim CEInfo Análise nº 3, 2009: Impacto do câncer no Município de São Paulo, São Paulo: CEInfo, 2009, 32 p.
- Simon SD, Bines J, Barrios CH, et al. Clinical characteristics and outcome of treatment of Brazilian women with breast cancer treated at public and private institutions—the AMAZONE project of the Brazilian breast cancer study group (GBECAM). San Antonio Breast Cancer Symposium 2009; San Antonio, TX, USA; Dec 11, 2009. Abstr 3082.
- Coleman MP, Quaresma M, Berrino F, et al. Cancer survival in five continents: a worldwide population-based study (CONCORD). *Lancet Oncol* 2008; 9: 730–56.
- Instituto Nacional de Câncer. Controle do câncer de mama: documento de consenso. Rio de Janeiro, Brasil: Ministério da Saúde, 2004

- Ministerio de Saude. National Policy for Oncological Care – Ministerial Resolution PT/GM GM nº 2439, December 8, 2005. http://www.saude.mg.gov.br/atos_normativos/legislacao-sanitaria/estabelecimentos-de-saude/oncologia/Portaria2439.pdf
- Instituto Brasileiro de Geografia e Estatística, Diretoria de Pesquisas, Coordenação de População e Indicadores Sociais, Pesquisa de Assistência Médico-Sanitária 2009.
- International Atomic Energy Agency. Directory of radiotherapy centers by country and region. <http://www-naweb.iaea.org/nahu/dirac/query.asp> (accessed April 20, 2012)
- Simon SD, Bines J, Barrios CH, et al. Clinical characteristics and outcome of treatment of Brazilian women with breast cancer treated at public and private institutions—the AMAZONE project of the Brazilian breast cancer study group (GBECAM). San Antonio Breast Cancer Symposium 2009; San Antonio, TX, USA; Dec 11, 2009. Abstr 3082.
- Alexandru Eniu et al. Breast Cancer in Limited Resource Settings: Treatment and Allocation of Resources. Breast Health Global Initiative. The Breast Journal, Volume 12 Suppl. 1, 2006 S38–S53

Reference Maps

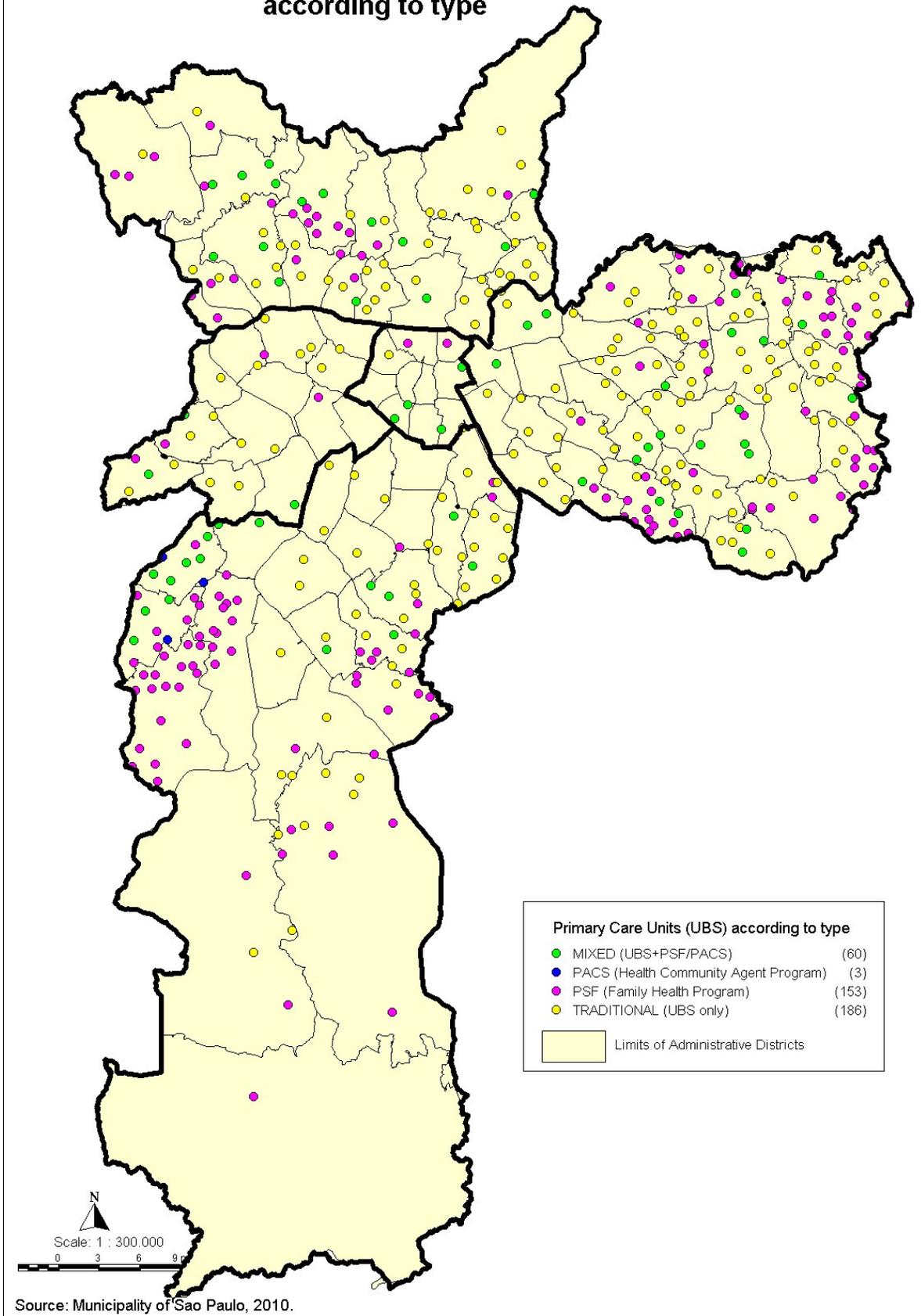


Municipality of Sao Paulo
Demographic Density, 2011.

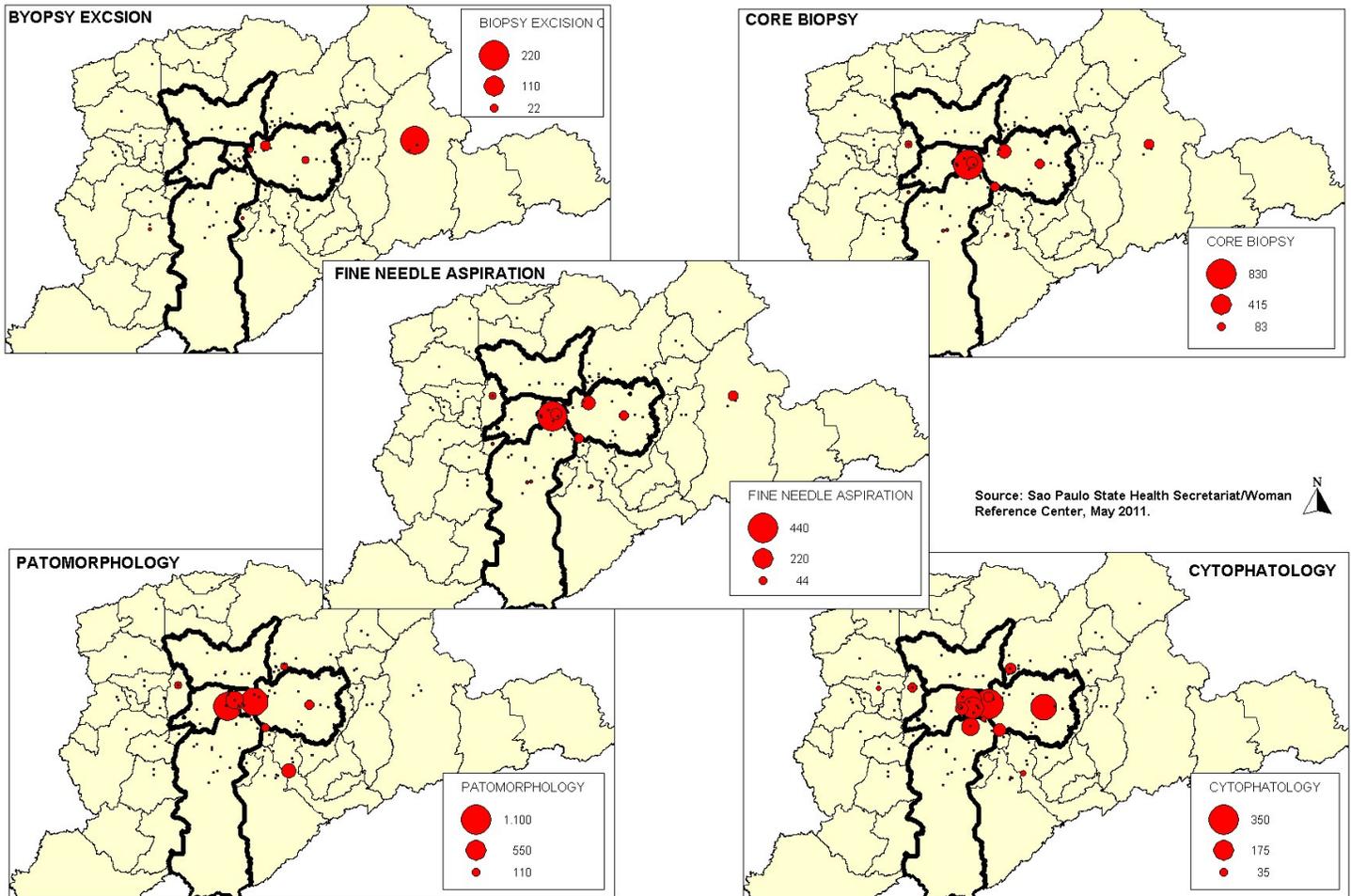


Source: IBGE - Brazilian Institute of Geography & Statistics, 2010.

Municipality of Sao Paulo Distribution of Health Primary Care Units (UBS) according to type



Metropolitan Area of Sao Paulo - Localization of Services and the Volume, 2011



Key Informant List

ORGANIZATION	NAME	POSITION
Fundação Oncocentro de Sao Paulo (FOSP)	Dr. Karina Braga Ribeiro	Epidemiologist
Sao Paulo State Health Secretariat	Dr. Karina Calife	Director, Women's Health Program
Sao Paulo Municipal Health Secretariat	Dr. Luiz Carlos Pazero	Doctor, Women's Health Technical Area
Sao Paulo Municipal Health Secretariat	Júlio Mayer de Castro Filho	Coordinator (former), Women's Health Technical Area
Pérola Byington Hospital	Dr. Luiz Henrique Gebrim	Technical Director, Department of Health
Pérola Byington Hospital	Dr. Jorje Shida	Chief Mastologist
Brazilian Society of Mastology Cancer Institute of the State of Sao Paulo (ICESP)	Dr. Carlos Alberto Ruiz	President Attending Physician at ICESP
Villa Nova Cachoeirinha Hospital	Dr. Maria Del Carmen G Molina Wolgien	Chief Mastologist
Villa Nova Cachoeirinha Hospital	Dr. Ana Maria Monteiro de Souza	General Manager, Maternity Ward
Villa Nova Cachoeirinha Hospital	Dr. Augusto Cezar Oliveira Andrade	Coordinator, Diagnostic and Therapeutic Services
Villa Nova Cachoeirinha Hospital	Valeria Rondineli	Coordinator, Health Integration Network
The Institute of Oncoguia	Lucian Holtz	President
Se Toqua Institute	Alexandre Travassos	Executive Manager

