SISMAMA—Implementation of an information system for breast cancer early detection programs in Brazil

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ABSTRACT

As national health systems seek to apply breast cancer screening recommendations to an entire population of women (within target age ranges for which there is evidence that screening reduces mortality), the volume of screening tests and resulting diagnostic investigations arising from abnormal test results—and the cost associated with them—will grow dramatically. Population-based early detection (screening) programs will need information systems and management tools to help these programs. This report describes Brazil's highly decentralized health care system and then describes in greater detail how the development and implementation of an information system for Brazil's nationwide breast cancer early detection program was carried out with input from various stakeholders. Challenges encountered in the implementation are shared. Preliminary findings from the first 1.5 million mammograms are presented to demonstrate the kind of provocative management information such a system can yield in a relatively short period of time. The potential of such information systems for improving efficiency, efficacy and cost-effectiveness of early detection programs is emphasized.

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Introduction

Cancer is the second leading cause of death in Brazil. With 49 new cases per 100,000 women, breast cancer is the highest incident cancer among Brazilian women. The age-standardized mortality rate from breast cancer has been climbing—reaching 10.9 per 100,000 women in 2007—and for over a decade has been the leading cause of death from cancer among Brazilian women.[1,2]

Actions to control breast cancer in Brazil began in the late 1980s as part of the initiative to promote Comprehensive Women's Health Services. In 2005, the Ministry of Health promulgated a National Policy for Cancer Care[3] which included a Plan for Controlling Cervical and Breast Cancers.[4] A 2006 Pact for Health[5] defined goals and the responsibilities of each level of government. The National Cancer Institute (INCA) coordinates cancer policies on a national level and has produced guidelines and technical materials for breast cancer control.[6,7] Among the strategic priorities in Brazil's cancer control plan was the strengthening of information systems that support the implementation and ongoing evaluation of early detection programs. The strategic importance of utilization and clinical data motivated INCA, in partnership with the Informatics Department of the public health care system (DATASUS), to develop the Information System for the Control of Breast Cancer (known by its Portuguese abbreviation SISMAMA: **SIS** for *Sistema*; **MAMA,** Portuguese for Breast) and a corresponding system for cervical cancer screening. SISMAMA was conceived as a management tool that would capture, organize and make available data about the population tested, test results, follow-up of abnormal cases, the quality of the services, as well as other essential information generated in the course of providing screening tests.

The goal of this article is to review how SISMAMA was implemented, and after a year of use, demonstrate preliminary findings. The experience of implementing SISMAMA can be instructive to other countries with national health systems contemplating expanding population-based cancer early detection programs.

It is not uncommon for successful pilot policy and programmatic innovations—even those interventions evaluated with scientific rigor—to fail when scaled up into national programs or campaigns. This may occur because the implementation process was not thoroughly planned. Implementation science seeks to understand

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the behavior of health administrators and other key players and stakeholders as fundamental elements in the identification, adoption and implementation of evidence-based interventions. Implementation science generates generalizable knowledge that can be applied in different settings and contexts.[8,9] This article, though not a report of implementation research per se, describes different phases of a process of development and implementation of a management tool—a novel information system—for a breast cancer early detection (screening) program in Brazil.

Brazil's universal health system, the *Sistema Único de Saúde* (SUS)

After two decades of dictatorship, a process of political democratization culminated in a new Federal Constitution of 1988 which established health as "a right of every citizen and a duty of the State" and mandated a universal health system, the *Sistema Único de Saúde* (SUS). The political and administrative decentralization determined by the new Constitution devolved considerable authority and autonomy to the State and Municipal governments.[10] The longstanding hierarchy of command in the relations between the federal government, state and municipalities was abolished in favor of a process by which policies and programs were formulated and prioritized by means of "pacts," agreements reached by "collegiate bodies" (representative entities) of each level of government, many with the participation of representatives of society. Formulas were established for the transfer of federal resources to states and municipalities, which also began to be responsible for part of the financing of SUS.

DATASUS and development and implementation of SISMAMA

To manage a universal health care system within a tripartite administration, the Informatics Department of the public health-care system, DATASUS, developed an information system that requires all public and private providers of services to SUS patients to report their service volume (and patient and service information) when they bill for reimbursement. The information is submitted at the municipal level, where it is reviewed and then forwarded to the state, where it is aggregated and approved subject to program criteria and budget caps, and then forwarded to the federal Ministry of Health for payment.

The DATASUS information system is divided into a hospitalization database and an ambulatory care database. SISMAMA was conceived in 2005 and first implemented in 2009, as a breast cancer subsystem of the ambulatory care information system. (See Table 1 for milestones.)

SISMAMA systematizes the collection of data about imaging and biopsy procedures utilized in the screening and diagnostic investigation of breast cancer. Billing for tests employed in the early detection of breast cancer—which encompasses both screening

tests and the subsequent diagnostic investigation provoked by abnormal screening results—is now an integral part of SISMAMA, making its use by most service providers, reimbursed on fee-for-service basis, mandatory. SISMAMA is, however, flexible; it can be used just for the evaluation and control of the supply of procedures, including services that are not reimbursed by SUS' ambulatory system, since alternative (legacy) forms of paying service providers persist.

SISMAMA's development started in 2005, and it was implemented nationwide by the Ministry of Health in 2009. The software development involved discussions among experts from various technical areas of the National Cancer Institute, such as public health, radiology, biomedical physics, mastology, and pathology, with input from the Brazilian College of Radiology. During the first phase of the development of the system in 2005, workshops were conducted with the participation of institutions and professionals recognized for their work in breast cancer control. Proposed specifications for database fields and data entry formats were circulated for critique.

In 2007, pilot testing of the system was carried out in anatomic pathology laboratories and radiology clinics in Rio de Janeiro. After initial validation, a national symposium was convened with representatives of the Secretaries of Health of various states, so that project coordinators from INCA and DATASUS could present SISMAMA, the plan for training users, and the strategies for gaining acceptance by professionals, imaging services, and laboratories. Training of professionals of the State and Municipal Secretaries of Health (SES and SMS) and the principal service providers occurred in 2008 in 26 states and the Federal District. The implementation process involved the state administrators responsible for cancer early detection programs in conjunction with the municipal coordinators, who in turn, were responsible for replicating the training at the municipal level. There were also training sessions for radiologists.

SISMAMA has two modules: one module for service providers, which is used by the breast imaging facilities and pathology laboratories to record the diagnostic tests performed (mammograms and ultrasounds, and breast cytopathology and histopathology, respectively), and to issue standardized radiology and pathology reports; and a second module for early detection program coordinators and managers, which is used by municipal, regional and state administrators. Data collection begins in the primary care setting, typically with a physician's order for a screening or diagnostic mammogram. Additional data are entered into the system as the services are provided and results generated.

For mammograms, SISMAMA generates a standardized report, including a BI-RADS® (Breast Imaging-Reporting and Data System) category in Portuguese, using the official translation of the Brazilian College of Radiology and Diagnostic Imaging.[11]

The management module permits 1) the oversight of breast cancer early detection actions, 2) follow-up of women with

Table 1
Milestones in the development of SISMAMA.

Date	Milestone
1988	Federal Constitution of Brazil establishes health as "a right of every citizen and a duty of the State"
1990	Universal health system, *Sistema Único de Saúde* (SUS) established
2005	National Policy for Cancer Care includes Plan for Controlling Cervical and Breast Cancers[3,4]
2005	SISMAMA development workshops conducted with institutions and professionals recognized for their work in breast cancer control
2006	Pact for Health makes breast cancer control a priority[5]
2007	Pilot testing of SISMAMA in pathology laboratories and radiology clinics in Rio de Janeiro
2007	National symposium includes representatives from municipal, state and federal ministries, as well as principal service providers
2008	Systems training of municipal and state government staff and principal service providers (radiologists) in 26 States and the Federal District
2009	Nationwide implementation by the Ministry of Health
2010	First data available for reports

abnormal results by means of a list of women with "positive" studies in each catchment area, and 3) the organization of a care network that fosters a "line of care" (i.e. a sequence of referrals) for comprehensive breast cancer care.

SISMAMA can generate management reports including quality control reports about mammography services, and about cytopathology and histopathology of breast biopsies provided by public facilities and private contractors. Using the system, municipal and state health administrators can see the clinical indications and the number of mammograms and breast cytopathology and histopathology examinations that have been provided. Having standardized screening test result reports and integrated them into SISMAMA, administrators can now evaluate the technical quality of services and the content of radiology and pathology reports, as well as measure waiting times for ordered procedures to be scheduled and performed and for results to be made available.

Screening is an effective strategy for reducing mortality from breast cancer if the program successfully reaches women in the target age range: aged 50–69 years. SISMAMA permits administrators to scrutinize the demographic attributes of those receiving screening services, those whose results are abnormal, and whether those with abnormal results get appropriate diagnostic follow-up.

Providers and health managers can have questions answered by contacting INCA or DATASUS staff via e-mail. SISMAMA Management Training Workshops are offered twice a year to staff at Municipal and State Secretaries of Health. Features being added to the system include technical and management manuals for download and web-based discussion forums for technical support for health professionals and administrators using the system.

Preliminary findings from the SISMAMA database

The first data about mammograms extracted from SISMAMA was submitted by 25 states and the Federal District for the period September 2009 through July 2010. A total of 1,510,639 mammograms were analyzed: 95% were screening mammograms and 5% were diagnostic mammograms.

About 50% of the screening mammograms were performed in women aged 50–69 years (the recommended screening age).

Despite the evidence of limited benefit and greater harm, 44% of screening mammograms were provided to women younger than age 50, a percentage viewed as excessively high, especially for a public system trying to expand access for women in the target age range.[12] (Fig. 1).

Analysis of SISMAMA data also found that the percentage of mammograms classified as BI-RADS category 1 (negative) was similar for diagnostic mammograms (42.4%) and for screening mammograms (45%). This finding was unexpected, given that diagnostic mammograms are ordered in cases where women already have symptoms or signs—such as palpable masses—suggestive of breast cancer. These unexpected statistics suggest possible errors in the documentation of the indication for ordering the mammogram or in the BI-RADS classification of mammograms reported by the radiologist. Both hypotheses warrant further investigation and suggest there may be a need for additional training. Another important, but expected, finding was that the proportion of examination results classified as BI-RADS 4 and 5 is greater for diagnostic mammograms than for screening mammograms in all age groups (Fig. 1).

SISMAMA data were used to monitor the "waiting time" between when a mammogram is ordered and when a radiologist's reading of the mammogram becomes available. The waiting time was up to 30 days for 66% of screening mammograms and 67% of investigational (diagnostic) mammograms (Fig. 2). The program's expectation for diagnostic mammograms is that the radiologist's report should be available for 90% within 30 days. These findings suggest that even though they accounted for only 5% of the mammograms captured by SISMAMA, diagnostic cases were not addressed with any greater urgency than screening mammograms.

These are examples of how SISMAMA data can be mined to generate various quality indicators and service indicators.

Remaining implementation challenges

One year after its implementation at a national level, the principal challenges for the implementation of SISMAMA involve issues related to staffing and training of managers of early detection (screening) programs and proper use of the system. During the
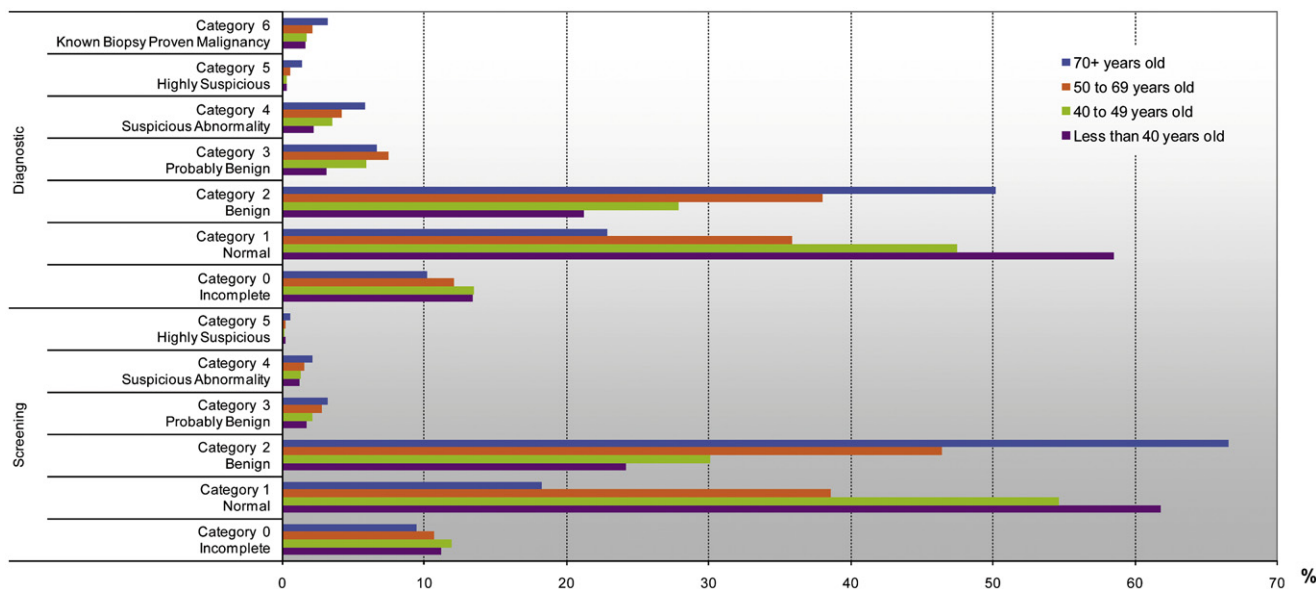

Fig. 1. Frequency distribution of BI-RADS® categories* according to age range and type of mammogram. Screening versus Diagnostic (investigational); SISMAMA data, Brazil, Sept. 2009 to July 2010. *BI-RADS Categories: 0 Incomplete; 1 Negative; 2 Benign; 3 Probably Benign; 4 Suspicious Abnormality; 5 Highly Suspicious; 6 Known Biopsy-Proven Malignancy.
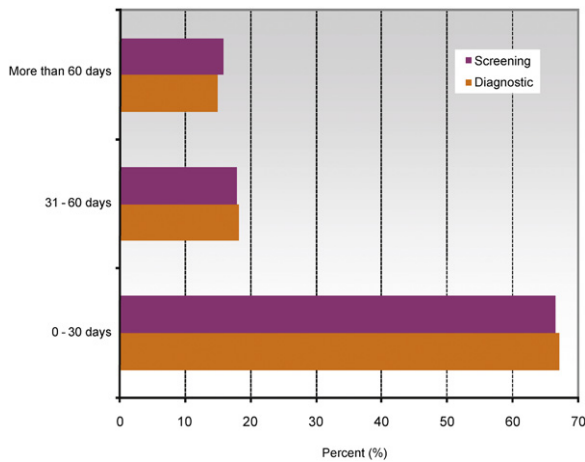
Fig. 2. Frequency distribution of the time (in days) between when a mammogram is ordered and when the radiologist's report becomes available. Comparing screening versus diagnostic mammograms; SISMAMA data, Brazil, Sept 2009 to July 2010.

initial implementation, some primary care physicians and radiologists accustomed to autonomy in their clinical practice and documentation objected to oversight of their data entry. Imaging studies and biopsies ordered by physicians must have accurate and complete demographic and clinical data. Similarly radiologists and pathologists issuing reports must make sure the information in SISMAMA is accurate. Ongoing training and monitoring is underway.

In its current configuration, SISMAMA software is installed at service providers' facilities—both public facilities and contracted imaging clinics and laboratories performing cytopathology and histopathology of the breast specimens—and at program management offices of the State and Municipal Secretaries of Health. New system architecture is planned that will provide a web platform, and new levels of management input are contemplated. The new design will optimize the capture of information of women with abnormal test results and make it easier for program managers to track these patients and make sure they receive appropriate investigation, diagnosis and treatment. Planning is underway so that, with future versions of the software, it will be possible to calculate population screening coverage based on records that track women who have been tested and not simply track individual mammograms or biopsies, a limitation of the current version.

Discussion

Before the implementation of SISMAMA, the only data available for monitoring the activities of breast cancer early detection programs in Brazil were service volume data generated by ambulatory information system of DATASUS, essentially the number mammograms performed. Monitoring any quality or outcome indicator was impossible.

With the consolidation of data within SISMAMA, it is now possible to assess various indicators against national standards or goals, and also to use indicators to compare relative performance across facilities, across service providers, and across states and populous municipalities. It will also be possible to compare quality indicators for mammography and cytopathology and histopathology against international benchmarks based on the experience of countries with more established screening programs. A program of cooperation and exchange is already underway between INCA and the Public Health Agency of Canada and collaborating provincial cancer agencies in Ontario and British Columbia.

Routine data entry into SISMAMA for the millions of mammograms financed by SUS each year will—in the space of just a few years—establish a massive database ripe for clinical epidemiology and health services research studies. The sheer scale of screening mammography in Brazil offers opportunities for randomized clinical trials to evaluate novel breast cancer screening technologies and interventions. Collectively this kind of investigation can contribute knowledge about the accuracy, effectiveness, efficiency, cost-effectiveness, and impact on clinical outcomes (mortality and 5-year survival) of large population-based breast cancer early detection programs.

In addition to supporting efforts to define standards, manage health information, monitor the quality of service providers, and foster evaluation and control, SISMAMA also has enormous potential as a regulatory tool, a feature that is particularly important in a public health care delivery system with a mixed network of public and private (contracted) service providers.

As more data are made public, health councils and organizations representing civil society, and indeed individual citizens, will be able to monitor the impact of initiatives to control breast cancer in their communities, and can help mobilizing those segments of the populations who have not been adequately screened.

Finally, there is the prospect—with an information system like SISMAMA tied to public financing strategies following evidence-based guidelines—of tackling the challenge of establishing organized breast cancer screening in a health system as decentralized as Brazil's. In this way it may be possible to break the present dichotomy of vertically structured programs or highly scattered activities in models where most screening is purely opportunistic.

Contributors statement

AMROF, LJP and LAS conceived the manuscript. DMAF, MBKD and JGT contributed to data collection and statistical analysis. MA, JGT, PFA, RCFS and LJP contributed to interpretation of results and manuscript writing and revision. All authors reviewed and approved the manuscript.

Conflict of interest and funding statement

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