

Cervical and Breast Cancer Brazilian Information System Coverage, 2008-2019

doi: <https://doi.org/10.32635/2176-9745.RBC.2022v68n1.1544>

Cobertura dos Sistemas de Informação dos Cânceres do Colo do Útero e de Mama no Brasil, 2008-2019

Cobertura de los Sistemas de Información sobre Cánceres del Cuello Uterino y de Mama en Brasil, 2008-2019

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ABSTRACT

Introduction: Cervical and breast cancer control have been monitored in Brazil through data available in the information systems recording screening and diagnostic investigation tests results. **Objective:** To evaluate the coverage of cervical and breast cancer control information systems in Brazil. **Method:** Cross-sectional study using data from cytopathological cervical exams, cervix and breast histopathology exams and mammograms recorded at Siscolo, Sismama, Siscan and SIA/SUS according to region and federative unit between 2008-2019. Annual proportions of exams informed only at SIA/SUS were calculated and descriptive analysis was performed among regions and over the years. **Results:** The coverage was higher for cytopathological cervical exams (loss of 20% in the period) and lower for histopathological breast exams (loss of 37.1% in the period). As of 2015, there was less coverage for all exams and in 2019 there were reduction of loss levels. **Conclusion:** The coverage of the systems varied over the period, being higher for cytopathologic cervical exams indicating that timing is an important factor of consolidation of the systems.

Key words: mass screening; health information systems; evaluation study; Unified Health System; indicators (statistics).

RESUMO

Introdução: Ações de controle dos cânceres do colo do útero e de mama têm sido monitoradas no Brasil por meio da utilização de dados disponíveis nos sistemas de informação que registram exames de rastreamento e investigação diagnóstica desses cânceres. **Objetivo:** Avaliar a cobertura dos sistemas de informação para o controle dos cânceres do colo do útero e de mama do Brasil. **Método:** Estudo transversal utilizando dados de exames citopatológicos do colo do útero, histopatológicos do colo do útero e de mama, e mamografias, registrados no Siscolo, Sismama, Siscan e SIA/SUS, segundo Região e Unidade Federativa entre 2008-2019. Calcularam-se as proporções anuais de exames informados apenas no SIA/SUS e realizou-se uma análise descritiva entre as Regiões e ao longo dos anos. **Resultados:** A cobertura foi maior para exames citopatológicos (perda de 20% no período) e menor para histopatológico de mama (perda de 37,1% no período). A partir de 2015, verificou-se menor cobertura para todos os exames e, em 2019, redução nos patamares de perda. **Conclusão:** A cobertura dos sistemas variou no período, sendo maior para citopatológicos do colo do útero, o que indica que o tempo é um importante fator na consolidação dos sistemas. **Palavras-chave:** programas de rastreamento; sistemas de informação em saúde; estudos de avaliação; Sistema Único de Saúde; indicadores (estatística).

RESUMEN

Introducción: Las acciones de control de los cánceres de cuello uterino y de mama han sido monitoreadas en Brasil mediante el uso de datos disponibles en los sistemas de información que registran los exámenes para detectar estos cánceres. **Objetivo:** Evaluar la cobertura de los sistemas de información para control del cáncer de cuello uterino y de mama en Brasil. **Método:** Estudio transversal que utiliza datos citopatológicos cervicales, histopatológicos cervicales y de mama y mamografías registradas en Siscolo, Sismama, Siscan y SIA/SUS según la región y Unidad Federativa entre 2008-2019. Se calcularon las proporciones anuales de los exámenes informados en el SIA/SUS y realizo análisis descriptivo entre regiones y lo largo de años. **Resultados:** La cobertura fue mayor para los exámenes citopatológicos (-20% en el período) y menor para histopatología mamaria (-37,1% en el período). Después de 2015, hubo menos cobertura para todos los exámenes y, en 2019, una reducción en los niveles de pérdida. **Conclusión:** La cobertura de los sistemas varió durante el período, siendo mayor para la citopatología cervical, lo que indica que el tiempo es un factor importante en la consolidación de los sistemas. **Palabras clave:** tamizaje masivo; sistemas de información en salud; estudio de evaluación; Sistema Único de Salud; indicadores (estadística).

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INTRODUCTION

The reduction of the incidence and mortality of breast and cervical cancer relies on early detection strategies. Nevertheless, high rates, mainly in low-and-mid income countries have been detected. For each year of the triennium 2020-2022, 16,590 new cases of cervical cancer and 66,280 of breast cancer are estimated for Brazil¹.

In order to evaluate and qualify their organized screening programs, some countries monitor coverage, quality of the exams and follow-up indicators⁵. Since the creation of a cervical screening pilot-program in the decade of 1990 in Brazil, the necessity to have data to follow-up the results emerged and in 1999, the Cervical Cancer Control Information System (Siscolo) was developed to register screening exams (cytopathological exam) and diagnostic confirmation (histopathological exam) offered by the National Health System (SUS), further to follow-up information about women with abnormal results. In 2009, the Breast Cancer Control Information System (Sismama) was implemented to register mammograms, cytopathological and histopathological exams in addition to follow-up information⁶.

In 2013, to improve and integrate these systems, the Cancer Information System (Siscan) was developed. The web system allows to identify the women through a SUS identification card and improve the follow-up of abnormal results specially by health units that beginning to use the computer-based system^{7,8}. These systems provide data to generate the required Ambulatory Information Form to pay the exams conducted by SUS^{6,8}.

After these systems were implemented, their data have been utilized to support the program management and critical analysis of the scenario of these types of cancer in the public system and elaboration of scientific publications⁹⁻¹⁷.

Loss of data, inferred by the difference between the number of the systems' registries and payment is one of the problems concluded by the studies which addressed the use of the information for cancer control¹⁸⁻²⁰ that impacts the coverage²¹. Although the literature recognizes the impact of these differences for a correct evaluation of breast and cervical cancer control actions, there are no studies measuring the differences among the registries at Siscolo, Sismama and Siscan and the SUS Ambulatory Information Form System (SIA/SUS) to pay the exams.

The aim of the present study was to evaluate the coverage of Siscolo, Sismama and Siscan in comparison with SIA/SUS billing process in Brazil's federation units between 2008 and 2019.

METHOD

Cross-sectional study with data from screening procedures and diagnostic investigation of breast and cervical cancer registered in SIA/SUS, Siscan, Siscolo and Sismama. Data were grouped by federation unit of the healthcare provider (laboratory or radiology clinic) and by year from 2008 to 2019. The time period was chosen considering the implementation of individualized records in the SUS²² ambulatorial health system for procedures related to breast and cervical cancers control, and the most updated data available.

The SIA/SUS is an administrative system utilized by the Ministry of Health to pay for outpatient procedures performed in SUS. Outpatient services providers need to send the payment archive monthly to be paid²³. Siscolo and Sismama were developed to have epidemiological information extracted from standardized forms used to order exams and results-request and report screening and diagnostic investigation tests essential to control these types of cervical and breast cancers⁶. Siscolo, Sismama and Siscan are related to SIA/SUS due to the issue of BPA-I containing the required information to pay exams which are imported by SIA/SUS^{6,8}.

According to SUS procedures list²², BPA-I files can only be accepted by SIA/SUS if generated solely by Siscolo, Sismama or Siscan^{7,24,25}. In addition to BPA-I, cancer systems also generate epidemiological data that should be sent to the coordination responsible to monitor cancer control actions. However, discrepancies in the flow of sending data of these systems⁶ and level of implementation²⁶ impact the number of exams registered (Figure 1).

Service providers of SUS utilizing Siscolo and Sismama generate two files at the end of the month, one with the ambulatory production containing the list of the exams completed and another with the epidemiological information extracted from standard forms. These files should contain the same number of exams, but it is possible that small differences exist since exams performed in disagreement with SUS billing rules, as below the minimum age, for example²⁷, are counted in the file with epidemiological information but not in BPA-I. However, problems in the routine of sending the files can cause major differences in the system's consolidated data¹⁸.

Service providers utilizing Siscan generate the BPA-I file at the end of the month and forwarded it to the billing system. The epidemiological data do not need to be sent⁸, and at the same time become available at the national base, allowing evaluation of breast and cervical cancer control actions and these information.

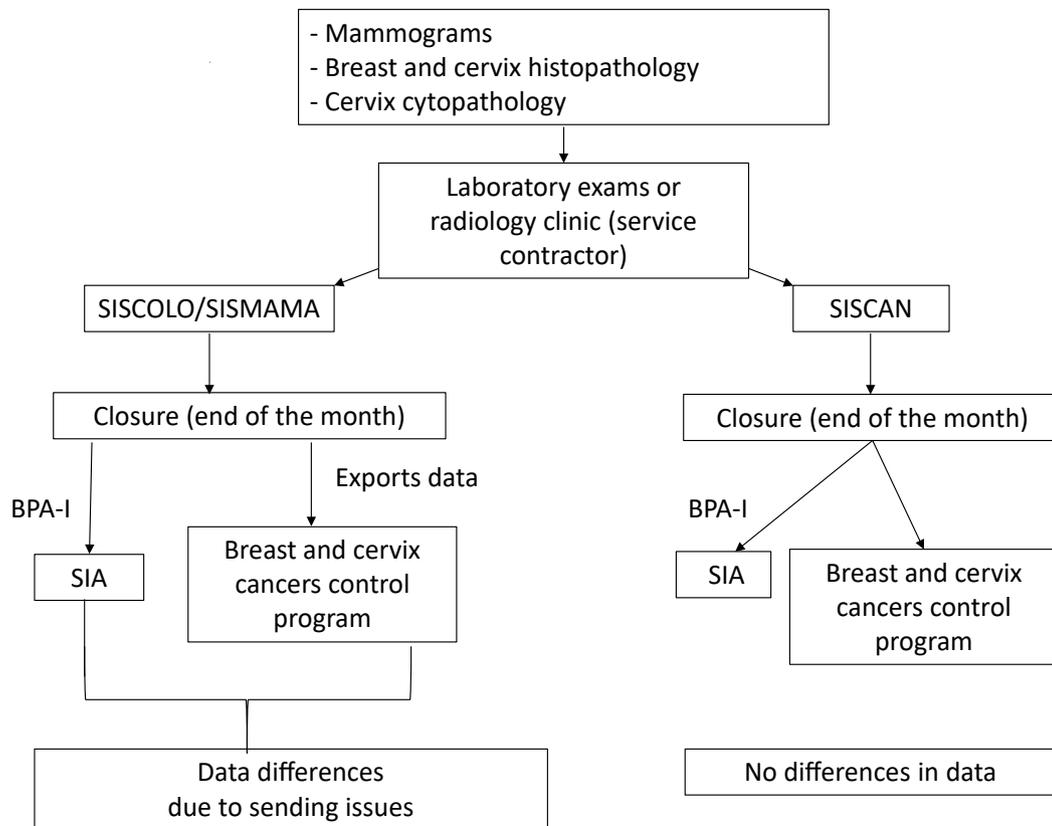


Figure 1. Flow of information from Siscolo, Sismama and Siscan and forwarded for payment until the consolidation at national bases

Captions: BPA-I = Ambulatory production form; SIA/SUS = Ambulatory Information System of SUS; Siscolo = Cervical Cancer Control Information System; Sismama = Breast Cancer Control Information System; Siscan = Cancer Information System.

Data of Siscolo, Sismama and Siscan were collected from Tabnet²⁸, the public domain tool of the Informatics Department of SUS (DATASUS) who provides unidentified epidemiologic information of these systems.

The number of cytopathological and histopathological exams of cervical cancer from 2008 to 2014 were extracted from Siscolo's Tabnet, and that from 2013 to 2019, from Siscan's. For the cervical anatomopathological exam – surgical piece, the comparative analysis was made since 2014 on, despite the procedure is registered at Siscan from 2013⁷. It was decided to include it in 2014, considering that few services had initiated the procedure of the cervix surgical piece at Siscan in 2013 (Chart 1).

Siscolo also included cytopathological exams for External Monitoring Quality (MEQ) which were registered at SIA/SUS between 2008 and 2014 with the same code of the cytopathological exam. Since 2014, the procedures to perform exams for MEQ were created at SIA/SUS. Because of the difficulty of identifying exams for MEQ at SIA/SUS in the initial period, these procedures were not included in the study.

The number of breast mammograms and histopathological exams were acquired from Sismama's

Tabnet from 2010 to 2014 and from Siscan from 2013 to 2019 (Chart 1).

As the epidemiologic data of Siscolo and Sismama are available at Tabnet until 2014, those common to Siscolo and Sismama or to Sismama and Siscan for 2013 and 2014 were added up.

The data registered at Siscolo and Sismama from 2015 henceforward could not be included in the analysis because they are unavailable from Tabnet and for this period, only the registries at SIA/SUS' Siscan were compared.

The data of production of exams of SIA/SUS are available at DATASUS webpage for public access. The following variables were considered: procedure, period of occurrence, code of National Registry of Healthcare Facilities and code of the federation unit where it is located. The number of procedures was extracted by the frequency to minimize possible problems of sub-quantification of the production²⁹, except for mammograms where the number of exams registered was adopted. It was not utilized the frequency of mammograms since the diagnostic exams are counted per breast radiographed and until two procedures can be registered²².

The number of exams registered at SIA/SUS was considered as reference because it is a payment system

Chart 1. Procedures, form of registration at the information systems of breast and cervical cancer and period when data were acquired by source.

Breast Cancer			
SIA/SUS	Sismama/Siscan	Periods	
Screening bilateral mammogram (code 02.04.03.18-8)	Screening mammogram	Sismama (2010 to 2014)	Siscan (2013 to 2019)
Mammogram (code 02.04.03.003-0)	Diagnostic mammogram		
Breast anatomopathological exam – biopsy (code 02.03.02.006-5)	Histopathological exam biopsy	Sismama (2010 to 2014)	Siscan (2013 to 2019)
Breast anatomopathological exam – surgical piece (code 02.03.02.007-3)	Histopathological exam – surgical piece		
Cervical cancer			
SIA/SUS	Siscolo/Siscan	Periods	
Cervicovaginal cytopathological exam/ microflora (code 02.03.01.001-9)	Cytopathological exam	Siscolo (2008 to 2014)	Siscan (2013 to 2019)
Cervicovaginal cytopathological exam/ microflora screening (code 02.03.01.008-6)*	Screening cytopathological exam**	Not included in Siscolo	Siscan (2013 to 2019)
Cervical anatomopathological exam – biopsy (code 02.03.02.008-1)	Histopathological exam – biopsy	Siscolo (2008 to 2014)	Siscan (2013 to 2019)
Cervical anatomopathological exam – surgical piece (code 02.03.02.002-2)	Histopathological exam – surgical piece	Not included in Siscolo	Siscan (2013 to 2019)

Captions: SIA/SUS = SUS Ambulatory Information System; Siscolo = Cervical Cancer Control Information System; Sismama = Breast Cancer Control Information System; Siscan = Cancer Information System.

(*) Procedure created at SIA/SUS since September 2014.

(**) Until August 2014, procedure 'cervicovaginal cytopathological exam/microflora (code 02.03.01.001-9)' at SIA/SUS.

where sub-notification is quite low. The data reported at SIA/SUS were compared with the data informed by service providers to Siscolo, Sismama and Siscan per federation unit and year of the exam.

The coverage of the cancer control systems was calculated according to federation unit, type of exam and year of registry through the proportion of exams registered in the cancer control systems and also at SIA/SUS, according to the following formula:

$$\text{Coverage} = \frac{\text{Exams at Cancer Control Information System}}{\text{Exams at SIA/SUS}} * 100$$

The indicator of loss of information shows the proportion of exams reported only at SIA/SUS per type of exam, year and federation unit calculated according to the formula:

$$\text{Loss of Information} = \frac{\text{Exams at SIA/SUS} - \text{Exams at Cancer Control Information System}}{\text{Exams at SIA/SUS}} * 100$$

The indicator “loss of information” shows the proportion of missing exams or not in the data of the epidemiologic information systems. Until 2014, it

reflected the proportion of exams paid and, due to flaws in shipping the data, were not counted at Siscolo and Sismama Tabnet. Since 2015, when only Siscan's data became available, the loss of information due to non-utilization of Siscan was clear further to continued use of Siscolo and Sismama, which stopped sending their data to the national base.

Comparative analysis among States and Regions was made. The graphic presentation per State excluded the values of loss of information below percentile 2 and above percentile 98 for better visualization.

According to the guidelines of the National Health Council (CNS) number 510, dated April 7, 2016³⁰, the submission to the Institutional Review Board was waived because only public secondary data without individual identification were utilized.

RESULTS

From 2008 to 2019, 97,353,388 cytopathological exams and 692,157 histopathological exams were registered at Siscolo and Siscan. From 2010 to 2019, 28,300,349 mammograms and 270,790 histopathological exams were registered at Sismama and Siscan.

In this same period, 121,567,939 cervical cytopathological exams, 866,284 cervical histopathological exams, 430,545 breast histopathological exams and 37,938,255 mammograms were entered at SIA/SUS.

Siscolo had the greatest coverage in the country for the period analyzed, 80.1% for cytopathological exams and 78.9% of histopathological exams but with important variations. The coverage for cytopathological exams ranged from 89.5% to 53.6% in 2010 and 2015, respectively. For histopathological exams, the greatest coverage of the system occurred in 2009 and 2010 (96.6% in each year) and the lowest in 2015 (43.8%).

For breast cancer control, the coverage was 74.6% for mammogram and 62.1% for histopathological exams in the country. The best system coverage for mammograms was in 2012 (84.6%) and for histopathology, in 2011 (99.1%) while the worst was in 2015 (46.6%) for mammogram and in 2016 (35.8%) for histopathology.

Similar to the country, 2015 presented the great difference among the system registries for most of the regions and exams. Payment of cytopathology exams had the lower information loss among the epidemiological systems in all regions until 2014. Losses were over 65% in the Southeast and North regions in 2015. The Midwest region was more stable from 2008 to 2017 and in 2018, Sisican had more entries than SIA/SUS. The South region lost 29% in 2014 with progressive reduction with greatest entry at Sisican from 2018 and the Northeast region lost 38% in 2015 with later reduction and inversion of the loss scenario in 2019 (Graph 1).

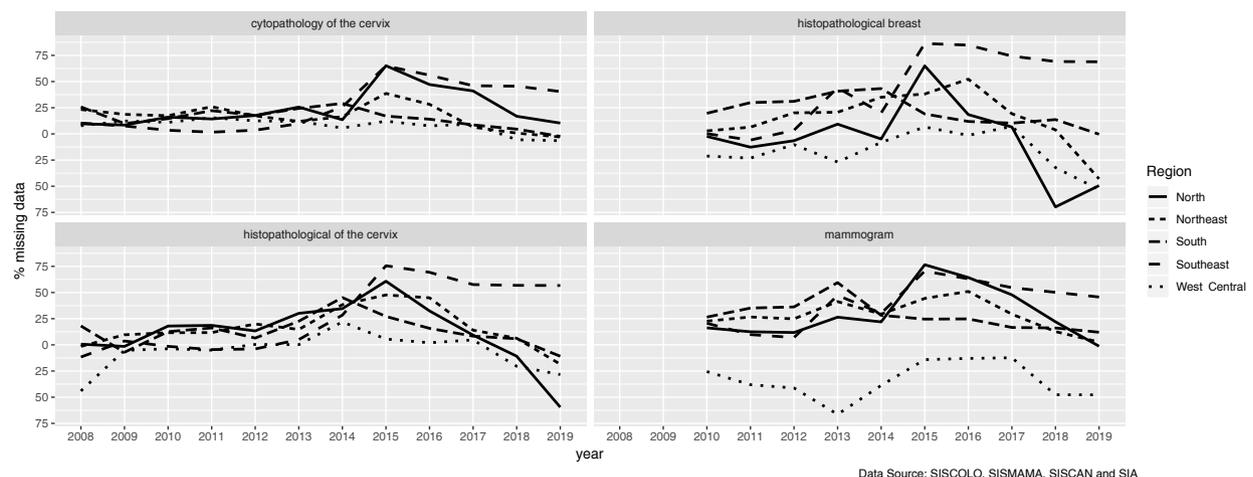
Midwest and Southeast regions presented higher percentage of cervical histopathological exam at Siscolo between 2008 and 2012, but from then on, differences were detected: in the Midwest, there was loss of data at

SIA/SUS between 2012 and 2017 and in 2018, data were presented at Sisican again and in the Southeast there were losses of 76% in 2015 and continued to register percentages over 50% until the last year of analysis. North and Northeast had losses too in 2015, 61% and 48% respectively, however, there was expressive drop of losses in the following years (Graph 1).

Breast histopathological exam had more variations. Until 2012, Midwest and North regions were more present at Sisican, the first kept this profile through the period analyzed, except in 2015 and 2017 with 7% of loss. In 2012, the Southeast reversed the pattern like the North region in 2013 and 2015 with losses over 60% in the last year, but in 2018 and 2019, registries in Sisican were over 50%. The South Region since 2014 started to show a pattern of loss reduction, in the Northeast there was a trend of increasing loss until 2016 with 52% and lowering henceforward until 2018 when it reached 4% (Graph 1).

Mammograms had more registries in Sisican for the Midwest through the whole period. In 2015, the North had loss at Sisican over 75% when compared with SIA/SUS ($p=0.948$). The South Region had progressive loss until 2013 and henceforward, a reduction was detected until 2019. In the Northeast, there was loss all through the period but reducing since 2016, reaching a deficit of 3% in 2019. In the Southeast, there was loss through the whole period, but higher in 2015 (70%), Graph 1.

The evaluation of the losses of registries at Siscolo per State, type of exam and year of exam show that the State of Espírito Santo was the only one with more registries in the cancer control program (Siscolo/Sisican) either for cytopathological or histopathological from 2008 to 2019 with low loss only in 2015. Mato Grosso do Sul had values quite similar in the information systems but increasing in



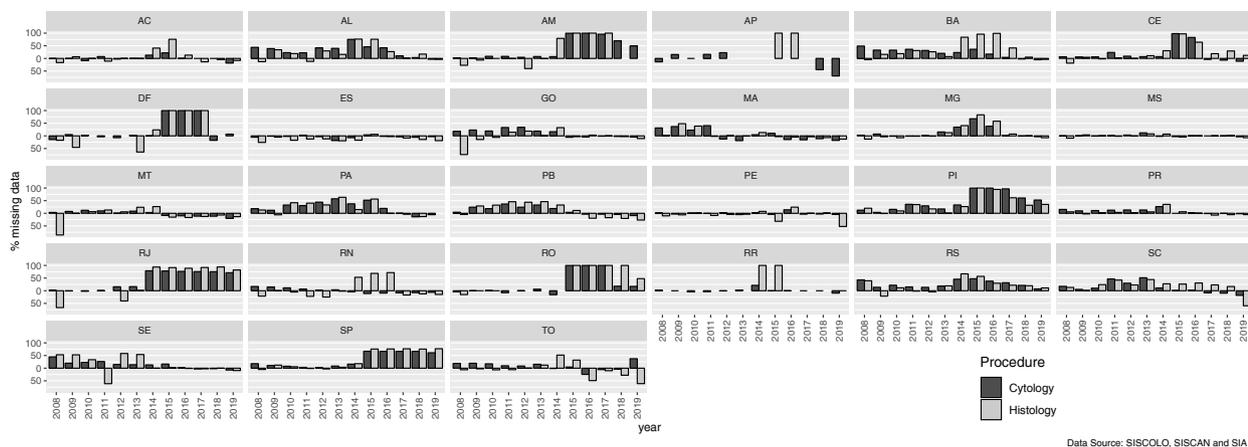
Graph 1. Loss of information of cervical and breast cancer control information systems according to the type of exam and region. Brazil, 2008-2019

Source: Tabnet²⁸.

2013 and 2014. Some States had low number of registries at Siscan from 2014 onwards as Amazonas, Rondônia, Piauí, Rio de Janeiro, Rio Grande do Sul and São Paulo. Other States with no loss or low proportion of loss until 2013-2014 increased the loss of data with reversion of this scenario in recent years: Federal District, Minas Gerais, Pará, Paraná, Paraíba and Tocantins. The States of Santa Catarina and Rio Grande do Norte reduced the loss from 2014 only for cervical cytopathological exams(Graph 2).

These States had quite different profiles when data about breast cancer, mammograms and histopathological

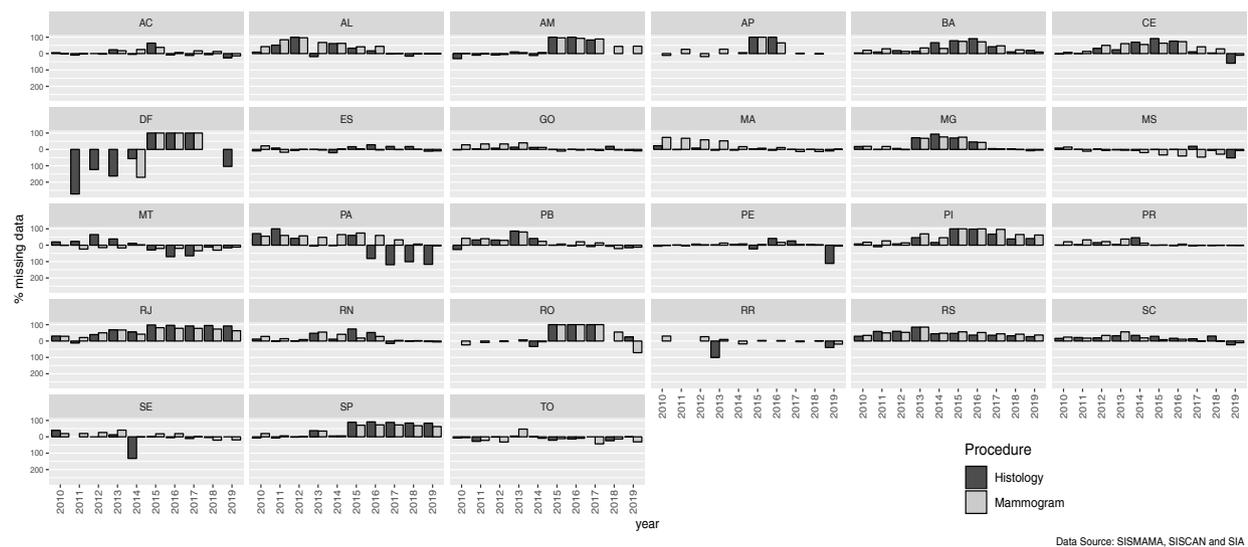
exams are evaluated. Mato Grosso had no loss since 2015 and Mato Grosso do Sul had losses of histopathological exams at SIA/SUS in 2010, 2012 and 2015. Tocantins, except 2013, had the same pattern, with a greater number of exams at Siscolo and Siscan. In the States of Maranhão, Goiás, Paraná, Santa Catarina, Sergipe and Paraíba, there was a change of the profile of losses since 2013-2014 with reduction or reversion of the concentration of exams reported. São Paulo and Rio de Janeiro, since 2015, presented expressive loss of the registries of these exams (Graph 3).



Graph 2. Loss of information of cervical cancer information system according to the type of federation unit of healthcare. Brazil, 2008-2019

Source: Tabnet²⁸.

Note: Cytopathological exams of Amapá 2016 (-277.04%) and 2017 (-662.95%) and histopathological exams of Rio de Janeiro of 2009 (-361.99%), 2010 (-362.26%) and 2011 (-168.55%); Rondônia 2014 (-87.32%); Federal District 2010 (-105.07%), 2011 (-267.95%), 2012 (-100.40%), 2018 (-471.43%) and 2019 (-130.62%) and Roraima 2011 (-100.0%), Pará 2019 (-139.24%) were excluded.



Graph 3. Loss of information of the breast cancer information systems according to the type of exam and federation unit of healthcare. Brazil, 2008-2019

Source: Tabnet²⁸.

Note: Mammograms of Roraima 2011 (-309.49%), Amapá (-2229.26%), Federal District 2010 (-428.27%), 2011 (-786.86), 2012 (-512.83%), 2013 (-470.32%), 2018 (-1176.87%) and 2019 (-650.85%) and histopathological exams of Sergipe 2011 (-278.57), Federal District 2010 (-291.76%) and 2018 (-549.56%) were excluded.

DISCUSSION

The quality of the data is an important feature of an information system impacting the planning if inaccuracies and discrepancy are found. Studies evaluating possible problems of the health programs information systems should be stimulated³¹ ensuring managers, the public and other users the required base to review them critically²¹.

There are references in the literature for completeness, reliability, validity and opportunity of quality investigated in Siscan^{32,33}, nevertheless, no study addressing coverage was found. The analysis of the differences in exams registries at the epidemiological and payment information systems allowed to check the coverage of these systems.

Differences among the registries of the epidemiological and payment information systems occur since their implementation and persist until today as the study results concluded. The differences of the number of registries varied along the period investigated, but the gradual implementation of Siscan since the last quarter of 2013 significantly impacted these differences. Since 2015 when Siscolo and Sismama data stopped to be exported to the national base, most of the States presented greater differences in the information although for some of them, Siscan was beneficial for epidemiological information.

Cervical cytopathological exam, a procedure with greater production among those analyzed, had the greatest volume of information possibly because Siscolo was the first implemented and its use is consolidated in the services' routine. From 2008 to 2014, this difference may be even lower since at SIA/SUS, since the second analyzes of some samples (MEQ) is counted as a cytology at SIA/SUS but it is not included in Siscolo's Tabnet. However, MEQ was limited to few States³⁴.

Anatomopathological exams had high losses of information and worst coverage which compromises the evaluation of the diagnoses, possibly due to the registry of these exams in other SIA/SUS procedures utilizing a code of anatomopathological exam performed in another anatomic site (020302003-0 – anatomopathological exam for freezing/paraffin per surgical piece or biopsy, except cervix and breast). Although SUS procedures explain that this code should not be used for billing cervical anatomopathology (C53) and breast (C50) exams²² of the diagnosis reported, the 10th International Classification of Diseases and Health-Related Issues (ICD-10)³⁵ was not applied and some laboratories registered ICD C50 and C53 in the procedure "anatomopathological exam for freezing/paraffin per surgical piece or biopsy, except cervix and breast".

There are no more available information of Siscolo and Sismama for comparison with SIA/SUS since 2015,

therefore it is possible to infer from Siscan registries that in these States the coverage is broader, and the implementation, satisfactory. High proportion of losses of epidemiological data can be associated with ample use of Siscolo and Sismama and the proportion would most likely reflect non-availability in these bases and not an actual loss.

Loss of information dropped in most of the States in 2018 and 2019, possibly reflecting the consolidation of the implementation of Siscan. However, Rio de Janeiro and São Paulo still have high percentage of loss for every year, which may be explained due to the continuous use of Siscolo and Sismama by the great laboratories that use their proprietary information systems and fail to feed Siscan²⁶.

In some States there were lower losses due to more registries in the epidemiological than in the payment systems. Most likely, States and Municipalities pay the services with their own funds, not with Federal resources^{29,36}; payment of the services by local managers remain unregistered at SIA/SUS but they are contingent on the registration of information in the epidemiological system, revision of procedures and off the payment deadline³⁷ and federal hospitals and universities pay with their own budget. Sub-registration at SIA/SUS occur because of the difference between revisions and off the payment deadline, while differences due to payments made locally or with own funds increase the registration in cancer control systems and can ensure compensation for actual losses.

Siscolo and Sismama data have been utilized in Brazil to monitor early detection and to support actions and public policies throughout the years. It was concluded that the time to consolidate its utilization was long since the lowest losses were found in Siscolo since 1999 and that the delayed process of implementation of Siscan impacted substantially the loss of data in Brazil, compromising the evaluation of the early detection and use of data to produce knowledge through scientific research. The intermittent feeding of the national base before the interruption of Siscolo and Sismama and the non-availability of an integrative tool among the great laboratories and Siscan are possibly the main factors for the large differences encountered.

It is advisable that the analyzes utilizing these systems are submitted to previous critical review of the coverage system locally and period analyzed and to what extent the analyzes can be affected. Preferentially, SIA/SUS data should be used in studies aimed to estimate the number of procedures or costs. The evaluation of the time series per federation unit should be monitored by the managers who with their teams must prioritize strategies to improve

the coverage of cancer control systems and the quality of the analyses.

The unavailability of the information of Siscolo and Sismama per States still utilizing these systems is a limitation of the study, which can impact the analysis in a few States.

Brazil is improving the full implementation of Siscan across the national territory and gradually the discrepancies among registries are being minimized already noticed in 2019. It is anticipated that in the upcoming years, Siscan data are able to reflect satisfactorily the coverage of actions for the early detection of cervical and breast by SUS and support management and research properly.

CONCLUSION

Loss of information of the registering systems of screening procedures and diagnosis of breast and cervical cancers occur since the implementation of these systems, impacting the analysis, monitoring and planning of cancer control actions. The initial period of implementation of the new system was critical. For being an online system, Siscan would potentially minimize the information losses, but the opposite occurred in the first years with great losses. Nevertheless, the gradual implementation of the system in the last years has been quite beneficial in reducing the loss of registries.

CONTRIBUTIONS

Jeane Tomazelli, Caroline Madalena Ribeiro and Maria Beatriz Kneipp Dias contributed substantially for the study conception and/or design, data acquisition, analysis and/or interpretation, wording and critical review. All the authors approved the final version to be published.

DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interests to declare.

FUNDING SOURCES

None.

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Recebido em 15/2/2021

Aprovado em 8/6/2021