

DATASUS and the challenges in the collection and dissemination of health information for the black population



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ABSTRACT

Health information with a racial cut is a relevant instrument for the planning of actions and interventions to combat social inequalities. Such information was indispensable for the formulation of the National Policy for the Integral Health of the Black Population. However, these data do not yet

present a completeness that allows analyzing the entire trajectory of the citizen in the health services at the municipal level. The article aims to present the difficulties of access and the gaps of completeness of the DATASUS data in the municipality of Camaçari, and to present a reflection on how these gaps hinder the estimation, dissemination, and application of indicators with racial focus for the follow-up and evaluation of inclusive health policies. Through quantitative methodology, an analysis of the available data on the use of health services with racial cuts, using the tabnet and tabwin systems, was carried out. It is demonstrated that most of the records ignore the question about the race-color of the users; The few who present it are insufficient to make a complete and reliable diagnosis.

Keywords: DATASUS, Race-color question, Black population, Racial indicators, Health.

1 INTRODUCTION

In 2001, the III World Conference against Racism, Racial Discrimination, Xenophobia and Related Intolerances was held in Durban, South Africa, which had as its product a Declaration and Plan of Action which presented a series of measures to combat racism in all sectors of social life, including health. Following the time frame, we also highlight the creation, in 2003, of the Secretariat of Policies for the Promotion of Racial Equality (SEPPIR), the social movements that guided the health of the black population, especially the Black Movement and the Women's Movement, began to have a differentiated dialogue with the government, enabling the incorporation of historical demands. According to the first Minister of SEPPIR, Matilde Ribeiro (2003-2008) the demands received in the health area, in this period, presented a well-structured content with the bases for the construction of a national policy, and it was up to the secretariat to promote and monitor the developments with the Ministry of Health. This process culminated in the establishment of the Comprehensive Health Policy for the Black Population, based on Ordinance No. 992, of May 13, 2009. (Santos, 2016)



In accordance with the National Policy on Health Information and Informatics (PNIIS), we can affirm that health information is a structuring element for universality, integrality, and social equity in health care. This represents a relevant instrument for the design, monitoring and evaluation of the results of social policies and for the planning of actions and interventions.

With regard more specifically to the health of the black population, such information was indispensable for the formulation of the National Policy for the Integral Health of the Black Population - PNSIPN, however these data do not yet present a completeness and dissemination that allows analyzing the entire trajectory of the citizen in the health services. The race-color question is fundamental for the collection of health information from the black population. From these indicators it is possible to visualize with greater precision the situation, the obstacles, and the advances of the PNSIPN. In addition to attention to the quality of collection of this information by health professionals, the way these data are estimated, used, and disseminated also needs to be evaluated.

The Department of Informatics of the Unified Health System – DATASUS, is institutionalized as the information technology agency, linked to the Ministry of Health, with the responsibility of collecting, treating, analyzing, and disseminating information in articulation with the municipal and state levels. However, some obstacles in the management of information technologies – IT, have hindered the performance of this department in the fulfillment of its functions and its functioning and access are still restricted to managers and need to be reorganized.

We will present in this article the difficulties of access and the gaps of completeness of the DATASUS data in the municipality of Camaçari, followed by a reflection on how these gaps hinder the estimation, dissemination and application of indicators with a racial cut.

This work is the product of the research *Racial Discrimination and Equal Rights: The implementation of the National Policy for the Integral Health of the Black Population and the Program to Combat Institutional Racism in the municipality of Camaçari, Bahia*, carried out with the support of CNPq and the Ministry of Health, and coordinated by Prof. Dr. Maria Cristina Gomes da Conceição.

2 METHODOLOGY

Through quantitative methodology, an analysis of the available data on the use of health services with racial cuts, was carried out. To capture the information by electronic means, the tabnet and tabwin data tabulation tools were used, accessible on the DATASUS website (<http://datasus.saude.gov.br/>) and for the elaboration of the tables the excel program was used.

This is a study of municipal scope, in which the data of the municipality of Camaçari on vital statistics of birth and mortality were analyzed. It is worth mentioning that the data on ethnicity and race, coming from the Information System on Live Births (SINASC) and the Mortality Information System (SIM) - Mortality and Live Births, should be collected through the heterodefinition, that is, in

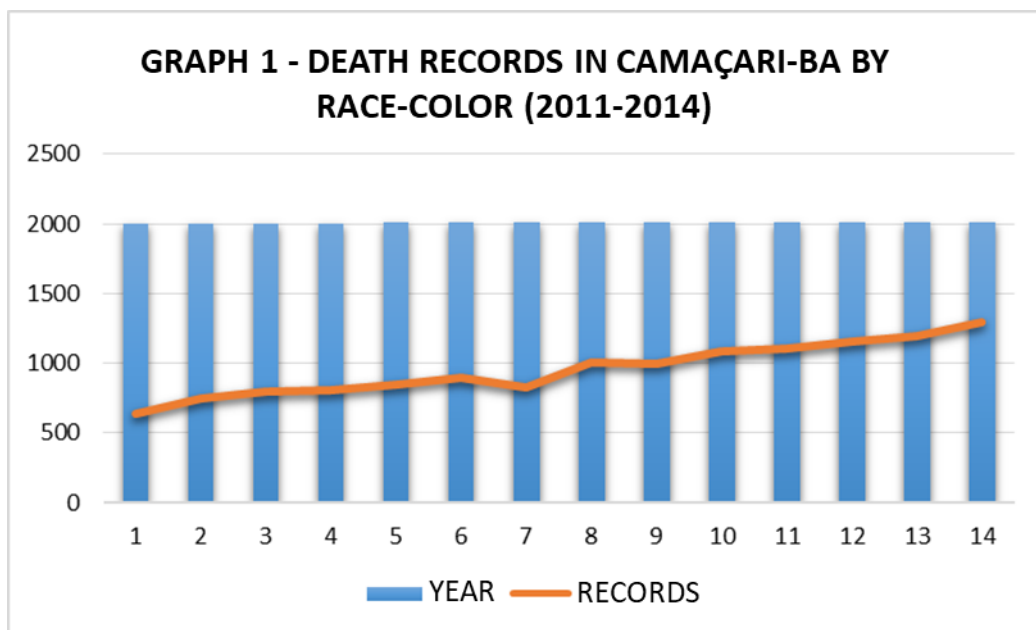


the absence or impossibility of the reference person to answer, the declaration of race/color should be made by another person, usually the health professional or the family member in charge.

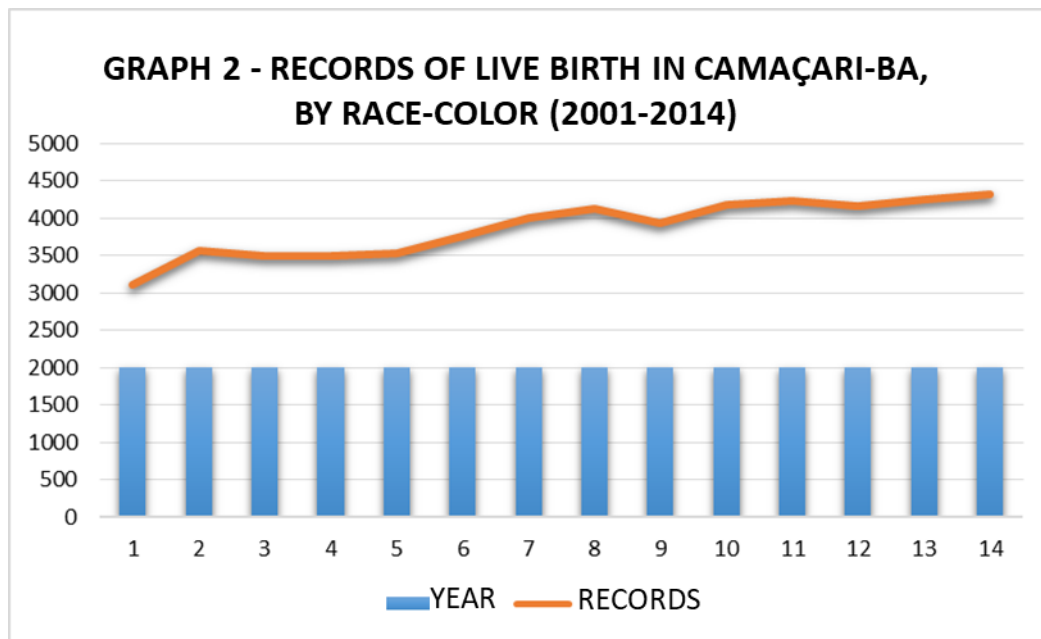
The data accessed during the research cover the period from 1996 to 2014, the most recent of 2015 and 2016 were not yet available. In this work, in view of the objective of analyzing the most current information and encompassing the period of most advances for affirmative action policies in the country, we made a time frame of the last 14 years and presented the data from 2001 to 2014.

3 RESULTS

Based on the analysis of the data collected, we can observe in Graphs 1 and 2 the gradual growth of records of the race-color item in the systems of vital events, during the years 2001 to 2014, in the municipality of Camaçari-Ba.



Source: Own estimates, based on MS/SVS/CGIAE - Mortality Information System - SIM



Source: Own estimates, based on MS/SVS/DASIS - Information System on Live Births - SINASC

Although this growth is considered an advance for the development of health information with a cut-off by race-color, it is worth noting that the completeness of this data is still limited when we analyze its coverage and quality. One of the relevant aspects when we analyze the coverage of the data is the inclusion of the "ignored" option among the possible answers, because at the time of filling out the question, employees tend to mark this category, for different reasons.

The history of racism in our country, as well as the issue of miscegenation that is often used to reinforce the myth of racial democracy is also reflected in the collection of this question. In health facilities, in many cases the forms do not have the question about race-color and, when they do, it is not valued or there is an embarrassment on the part of professionals and service users at the time of questioning and answering about race-color. In some cases, to avoid asking this question, professionals leave this item blank or, when there is the option "ignored" in the form, prefer to mark it or, if there is no such option, mark "not declared", compromising the collection of the data.

Another aspect that limits the quality of the data is the collection through heterodefinition. This method, which consists of the declaration of race-color made by third parties should only be used given the impossibility of self-declaration, which is the internationally recommended method and the most used by the IBGE in its research. This is the case of information on live births and death, which is usually declared by health professionals, or responsible family members, and may suffer cultural influences from these.

In the IBGE censuses and surveys, when asked the question about race-color, almost all the interviewees manage to fit into one of the five pre-established groups (white, black, brown, yellow, indigenous), and also manage to define the color of their children, elderly and disabled relatives. Several surveys were done to know if this question was reliable, or if it was better to ask another person



trained by the researchers to give their opinion on the color and race of the respondent. Comparing the results, it was concluded that the color given by the person himself was confirmed by the color given by another person in the vast majority of cases. And, most importantly, for ethical and dignity reasons, it is more appropriate for the individual to define himself. (Osorio, 2003). Currently, most people spontaneously answer one of the five colors defined by the IBGE, without the interviewer having to read the colors that are written in the questionnaire. Thus, it can be concluded that, to the extent that the race-color question becomes a common procedure in the services, there will be no estrangement on the part of the user population, nor of the professionals in care and, with this, new health policies can be thought of and the existing ones will be strengthened, based on the statistics generated.

According to Osório (2003), for the IBGE the category "black" encompasses people who declare themselves black or brown. Currently there is a great proximity between the term *moreno*, common in spontaneous responses, and the term *pardo*, one of the IBGE questions. Both terms represent the "middle ground", the miscegenation between whites and blacks, but the category "pardo" is still the most used, as we will see in the analysis of the data of vital events of the municipality of Camaçari-Ba.

Analyzing table 1, we can observe that from 2010, the number of records of newborns declared brown decreases slightly, while the number of newborns declared white and black increases considerably, with the largest increase observed among blacks, who even surpass the records of white newborns. This change demonstrates a greater openness to the racial definition of the black population, according to the objectives of the inclusive policies implemented in the country.

TABLE 1 - Number of live births in Camaçari-Ba by color-race, 2001-2014

| YEAR | WHITE | BLACK | YELLOW | BROWN | INDIGENA | IGNORED | TOTAL |
|--------------|-------------|-------------|------------|---------------|-----------|-------------|-------|
| 2001 | 85 | 48 | 17 | 2.874 | 11 | 80 | 3.115 |
| 2002 | 76 | 30 | 6 | 3.272 | 7 | 170 | 3.561 |
| 2003 | 54 | 14 | 33 | 3.226 | 6 | 159 | 3.492 |
| 2004 | 66 | 13 | 18 | 3.176 | 1 | 219 | 3.493 |
| 2005 | 58 | 15 | 8 | 3.329 | 2 | 129 | 3.541 |
| 2006 | 189 | 25 | 5 | 3.545 | 1 | 4 | 3.769 |
| 2007 | 161 | 30 | 9 | 3.794 | - | 8 | 4.002 |
| 2008 | 151 | 37 | 8 | 3.935 | - | 3 | 4.134 |
| 2009 | 104 | 30 | 6 | 3.767 | - | 34 | 3.941 |
| 2010 | 121 | 33 | 6 | 3.998 | 1 | 16 | 4.175 |
| 2011 | 295 | 314 | 23 | 3.520 | 5 | 85 | 4.242 |
| 2012 | 210 | 309 | 21 | 3.517 | 14 | 89 | 4.160 |
| 2013 | 246 | 292 | 17 | 3.574 | 4 | 124 | 4.257 |
| 2014 | 231 | 342 | 20 | 3.605 | 6 | 118 | 4.322 |
| TOTAL | 2047 | 1532 | 197 | 49.132 | 58 | 1238 | |

Source: Own estimates, based on MS/SVS/DASIS - Information System on Live Births - SINASC

In the records of deaths, in table 2, we observed that in the period analyzed the majority was also defined as brown, and what draws the most attention is the decrease in cases with ignored color,



reinforcing the tendency to a racial definition, which still needs to continue to be worked on to improve the coverage and quality of records and information with racial cut.

TABLE 2 - Number of deaths in Camaçari-Ba by color-race, 2001-2014

| YEAR | WHITE | BLACK | YELLOW | CURTAIN | INDIGENOUS | IGNORED | TOTAL |
|--------------|-------------|-------------|-----------|-------------|------------|------------|-------|
| 2001 | 84 | 88 | - | 360 | - | 107 | 639 |
| 2002 | 92 | 125 | 1 | 386 | - | 142 | 746 |
| 2003 | 102 | 121 | 2 | 468 | - | 99 | 792 |
| 2004 | 133 | 134 | 1 | 465 | 1 | 69 | 803 |
| 2005 | 114 | 119 | 1 | 548 | - | 68 | 850 |
| 2006 | 131 | 142 | 1 | 573 | - | 49 | 896 |
| 2007 | 137 | 119 | 1 | 518 | - | 49 | 824 |
| 2008 | 161 | 196 | 2 | 603 | - | 42 | 1.004 |
| 2009 | 154 | 182 | 1 | 624 | - | 38 | 999 |
| 2010 | 177 | 188 | - | 679 | - | 44 | 1.088 |
| 2011 | 188 | 176 | 2 | 691 | - | 48 | 1.105 |
| 2012 | 171 | 197 | 1 | 731 | - | 58 | 1.158 |
| 2013 | 194 | 205 | 1 | 746 | 1 | 44 | 1.191 |
| 2014 | 207 | 195 | 2 | 847 | 2 | 38 | 1.291 |
| TOTAL | 2045 | 2187 | 16 | 8239 | 4 | 895 | |

Source: Own estimates, based on MS/SVS/CGIAE - Mortality Information System - SIM

In this study it was possible to analyze only the available data with a reliable coverage: of births and deaths. The other information systems on prevention and care have a higher rate of non-response or "ignored" race-color.

For this reason, with regard to the challenges of access and dissemination of information with racial cut, we understand that it is important to reflect on the advances and limitations of DATASUS in the management of Information Systems.

According to the Master Plan for Information Technology – PDTI, a document prepared by the Ministry of Health that presents the diagnosis and planning of technological resources for the years 2014 and 2015, although DATASUS is the central IT body in the Ministry of Health located in the Federal District, the management of this process is not limited to the department. This is due to the large number of autonomous centers that do not always act in an integrated manner to the technological and regulatory processes of DATASUS, compromising the safety and quality of the services provided by the department.

In this sense, the PDTI itself states that there are islands of information management, which function as independent systems within the IT of the Ministry of Health. For example, the user identification database does not connect with the databases on consultations, hospitalizations, tests, diagnoses, surgeries, among others. This disconnect between the information bases in the areas of prevention, care and management demonstrates the difficulty of DATASUS, as a central body, to balance and meet the specific needs of municipalities and states, respecting the principle of



decentralization of the SUS, without harming the surveillance, standardization and integration of the computerization of health systems. It also demonstrates the existence of barriers to access to the information produced to generate scientific evidence and production of research for the follow-up, evaluation of results of health policies and promotion of equity, in addition to hindering social control by the population.

We also note, in the aforementioned document, that there is no certainty as to the number of Information Systems managed by DATASUS. It is stated that there are about 171 information systems, divided into health systems, with emphasis on internal policies and systems related to the management of the Ministry, the PDTI 2016 speaks of "hundreds" of systems. However, when accessing the department's website, (<http://datasus.saude.gov.br/>) we found available only 42 systems divided into: national, epidemiological, outpatient, social, regulatory, financial, hospital, structuring and vital events systems, and not most do not present the data by race.

In an attempt to develop greater integration between these national systems and improve data dissemination, DATASUS developed the tools TabWin, TabNet, and Cadernos de Informações em Saúde, but these are insufficient in the current organizational scenario of the department. Despite this advance, access to this data is limited and, in some cases, restricted to health workers. This limits social control and the conduct of studies based on these data. With regard to racially charged information, its completeness is even more incomplete, because the question about ethnicity-race is absent in most of the formats present in services at all levels of care and management, hindering the right of researchers to access the data stored in DATASUS and limiting the coverage and quality of records by race-color.

4 FINAL CONSIDERATIONS

Given the analysis of the data presented and the reflection on the importance of the racial cut in data collection for information systems and the gaps of DATASUS in data management, we conclude that it is necessary a joint effort of managers and other health workers, from the three levels of government, especially the municipalities, to carry out actions aimed at fostering better collection, with revision of forms, and a better use of health information.

As we have seen, at the national level interventions are already being carried out with the objective of developing the integration and interoperability of health systems, to improve the coverage and dissemination of data. However, due to the intensity and complexity of these gaps in the central scope of DATASUS management, and the urgency of generating indicators in the health of the black population, it is necessary that municipal administrations develop their own means to generate their own information with a racial cut and, thus, produce scientific evidence to evaluate the implementation, results and impact of the PNSIPN.



In this perspective, it is up to the municipal and state management to provide the necessary structure and instruments for the health team to collect data and promote local information systems. This means inserting the race-color item in all SUS forms and documents and also encouraging private establishments, as well as promoting and collaborating with permanent education actions including the theme of the health of the black population and institutional racism in training. It is important that management also stimulates the production of knowledge on this theme, encouraging research and work that aims to contribute to the implementation of the PNSIPN. Properly trained and instrumentalized, it is up to the health professionals the technical responsibility in the collection of the question, to guide the users on the IBGE classification standards and to respect and encourage the self-declaration of the race-color and to correctly make the heterodefinition when necessary.

In addition, it is important to foster the creation of local information systems that can not only meet the demands of the Ministry of Health but also local needs, from a municipal database that allows analyzing the entire trajectory of the citizen in health services with attention to the racial cut of these data.

In this sense, the research project "Racial Discrimination and Equal Rights: The implementation of the National Policy for the Integral Health of the Black Population and the Program to Combat Institutional Racism in the Municipality of Camaçari, Bahia", after a diagnosis of the completeness of the municipality's data by race-color, offered training on this theme to health professionals and worked with managers to develop a pilot information system that can serve in the future for the construction of a municipal database.

It is important to highlight the efforts of professionals who understand the importance of information for the services, such as a worker from the Support Unit for People with Sickle Cell Disease (UNIFAL) of Camaçari-Ba who developed, with few resources, an internal system in the unit for control and monitoring of the users served, with a breakdown by race-color. This shows, therefore, that it is possible to create possibilities to ensure the implementation of the Comprehensive Health Policy of the Black Population, improve the provision of services to this group and also the production of ethnic-racial indicators and, as a consequence, generate scientific evidence that contributes to promote racial equity in health.

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REFERENCES

- BARBOSA, Elisana Lisboa. DATASUS: A disponibilidade e relevância da informação racial para diminuir as desigualdades na saúde. Salvador, 2016.
- BRASIL. Ministério da Saúde - DATASUS/SGEP/MS. Plano Diretor de Tecnologia da Informação do Ministério da Saúde 2016. Brasília-DF, 2016.
- BRASIL. Ministério da Saúde. Política Nacional de Informação e Informática em Saúde. Editora: Ministério da Saúde – Brasília, 2016.
- BRASIL. Ministério da Saúde. Política Nacional de Saúde Integral da População Negra uma política do SUS. 2ª edição – 2013.
- OSORIO, Rafael Guerreiro. O sistema classificatório de “cor ou raça” do IBGE. Brasília, 2003.
- SANTOS, Katia Regina da Costa (Org.); SOUZA, Edileuza Penha (Org.). SEPPIR - Promovendo a Igualdade Racial para um Brasil sem Racismo. 1ª Edição Brasília, 2016.