

Filling out the race/skin color item in the patient identification form: aspects of its implementation in a university hospital

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Abstract *Thirteen years after the publication of the National Policy for the Comprehensive Health of the Black Population (PNSIPN, Política Nacional da Saúde Integral da População Negra), filling out the race/skin color question in the patient identification form remains a challenge. Authors have focused on the need to integrate knowledge from the science of implementation into public policies. The aim of this article is to describe and analyze the implementation of the collection of the race/skin color item carried out by the professionals responsible for the registration of patients at a university hospital in the city of São Paulo. This was an exploratory and descriptive study, structured from three constructs of the Consolidated Framework for Implementation Research (CFIR): intervention, internal scenario and characteristics of individuals. Most records of race/skin color in the observed institution are made by heteroidentification. Based on the CFIR constructs, aspects identified as obstacles and facilitators are identified. The implementation of the collection of the race/skin color item by self-declaration, as provided for in the PNSIPN and in Ordinance n. 344/2017, is still incipient and depends mainly on organizational changes, which can favor its effectiveness.*

Key words *Racial/ethnic classification, Black population health, Public health policies, Health care research, Implementation science*

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Introduction

The year 2022 marks the 134th anniversary of the abolition of slavery in Brazil, which lasted 388 years¹. During the entire period of enslavement, slavers dehumanized black individuals in a systematically programmed manner, preventing them from having any rights². Amidst the centenary of the abolition of slavery in Brazil, under the concept of “collective health” in the 1970s, 80s and 90s, the use of “inequality” was debated as a determinant of health. This construction is based on classificatory models, which proposed the understanding of the distribution of diseases and illnesses in the population by introducing stratified variables, such as income, occupation and schooling, thus resulting in the concept of “social class”. This concept emerged to overcome the conception of population as a simple sum of individuals³.

Nevertheless, it was only at the end of the 20th century that studies in the health area started to indicate race/ethnicity as an important social determinant of health, demonstrating disparities in health access and disease evolution⁴. A growing scientific production highlights racism as a booster of several social factors that perpetuate racial inequalities in health⁵⁻¹⁴. Several authors consider race, skin color and ethnicity as fundamental dimensions to understand the distribution of health outcomes, with important implications in terms of public policies¹⁵.

A series of black social movements in search of better living conditions earned the inclusion of health as a universal right in the Brazilian Federal Constitution of 1988¹⁶. In this context, aiming to promote the well-being of all people, without any prejudice related to origin, race, gender, skin color, age and any other forms of discrimination (Brazil, 1988, art. 3, item IV), the Brazilian Unified Health System (SUS, *Sistema Único de Saúde*) was created (Federal Law N. 8080, of September 19, 1990)¹⁷. The black and brown population reached 55.8% of the Brazilian population in 2018¹⁸ and has grown since the implementation of the self-declared race/skin color item by the Brazilian Institute of Geography and Statistics (IBGE, *Instituto Brasileiro de Geografia e Estatística*) in 1991¹⁹. In Brazil, 67% of the black population and the 47.2% of the white population were covered by SUS in 2008²⁰.

The race/skin color item was first implemented in the Health Information System (SIS, *Sistema de Informação de Saúde*) by the City of São Paulo in 1990, through Ordinance n. 696/90^{21,8},

which became, in the words of Fátima Oliveira, “the most important political achievement of the Black Movement in the health area”²².

In Brazil, the National Policy for the Comprehensive Health of the Black Population (PNSIPN, *Política Nacional de Saúde Integral da População Negra*)²³, based on the principles of equity in health, was established by the Ministry of Health through Ordinance GM/MH n. 992, of May 13, 2009. The PNSIPN is characterized by the “acknowledgement of racism, of ethnic-racial inequalities and institutional racism as social determinants of health conditions”. Its objective is “to promote the comprehensive health of the black population, prioritizing the reduction of ethnic-racial inequalities, the fight against racism and discrimination in SUS institutions and services”²³. This policy recommends the inclusion of the skin color item in all data collection instruments of public services and suggests the analysis of data disaggregated by race, skin color and ethnicity.

Years later, going in the same direction, Ordinance n. 344 of 2017 of the Ministry of Health (MH)²⁴ was established, which made the collection of the race/skin color item mandatory and through self-declaration²⁵. The mandatory collection of the race/skin color item by health services supports the identification of determinants of the health-disease process, health inequalities and the impact of actions and programs to reduce inequities. A reliable database is required, which can support and direct decision-making instances²⁶.

Despite the recommendations of the PNSIPN and Ordinance n. 344, during the recent health crisis caused by the COVID-19 pandemic, the race/skin color item was not included in the first epidemiological reports published by the Ministry of Health, even though it was included in the notification forms for influenza syndrome and for severe acute respiratory syndrome (SARS)²⁷.

The literature points out the challenges involved in the implementation of interventions²⁸, especially when related to social determinants^{29,30}, such as the racial issue. The critical race theory (CRT) draws our attention to the main characteristics to be observed in research on racial inequality, such as racialization, racial awareness, social location and the intention to eliminate this inequality³¹. In parallel, the international literature has pointed out the need to integrate the knowledge of implementation science (IS) to public policies, focusing on health. Among the instruments used in IS, the Consol-

idated Framework for Implementation Research (CFIR) stands out, being adopted in its entirety or in part³².

Few articles were found on the quality and compliance with filling out the race/skin color item in Brazil³³⁻³⁶, with most articles originating from the United States^{29,30,37}. There is a knowledge gap here about the adequacy of the race/skin color item collection in health databases, which as part of a public policy affects the monitoring, evaluation and implementation of other interventions aimed at the health of the black population and, consequently, the fight against institutional racism in health.

Objective

The present study aimed at describing and analyzing the implementation of the filling out of the race/skin color item carried out by professionals in the patient registration sector of a hospital in the city of São Paulo, state of São Paulo, Brazil.

Method

The present was an exploratory and descriptive study based on the Implementation Science. The study was structured based on the Consolidated Framework for Implementation Research (CFIR)²⁸.

CFIR is one of the tools used to systematically assess the context in which implementation takes place, through implementation constructs and domains considered to be moderators, which influence the implementation outcomes³⁸⁻⁴⁰. Three instrument constructs were used, as depicted in Chart 1.

The present study was divided into two moments, using two instruments. The first was the follow-up of the service, focusing on the collection and filling out of the race/skin color item carried out by the employees of the registration sector. This follow-up was carried out by one of the researchers, a self-declared black man, in his penultimate undergraduate year in a course in the health area. The follow-up took place from October 2021 to March 2022 and included the creation of a field diary that recorded the researcher's perceptions about the service, from the way he was received; the interactions between employees and patients; time of each consultation; doubts raised by patients; and impressions and questions raised by the observer. The data

were analyzed and discussed by the group of authors, consisting of men and women, five of them black.

The service has adopted an electronic system for patient registration since 1994, with the following information as mandatory fields: Name (open field), age (open field), race/skin color, gender, level of schooling and marital status. The item on race/skin color has the following options when filled out: YEL (yellow), WHI (white), IGN (ignored), IND (indigenous), MUL (mulatto), COL (colored), BLK (black). The flow of patient care is explained in Figure 1.

The second moment consisted of the filling out of a questionnaire by the service's employees, between December 2021 and February 2022. This instrument was developed by the researchers, with 14 open and closed questions, aimed at demographic characterization, time working in the service, experience with the collection of the race/skin color item and with the public policy related to it.

This study was evaluated and approved by the Research Ethics Committee, in accordance with Resolution n. 466/12 of the National Health Council, under Opinion n. 4,924,185 of August 2021.

Results

All six employees of the registration sector agreed to participate in the research and signed the Free and Informed Consent (ICF) form. The characterization of these employees will be carried out throughout the results.

A total of 107 observations were made, of which 17 were excluded because they used data imported from another information system, which had been collected at another moment. On average, the registration of each patient took 11 minutes, and the observer remained, in total, 20 hours at the place where the patients were registered.

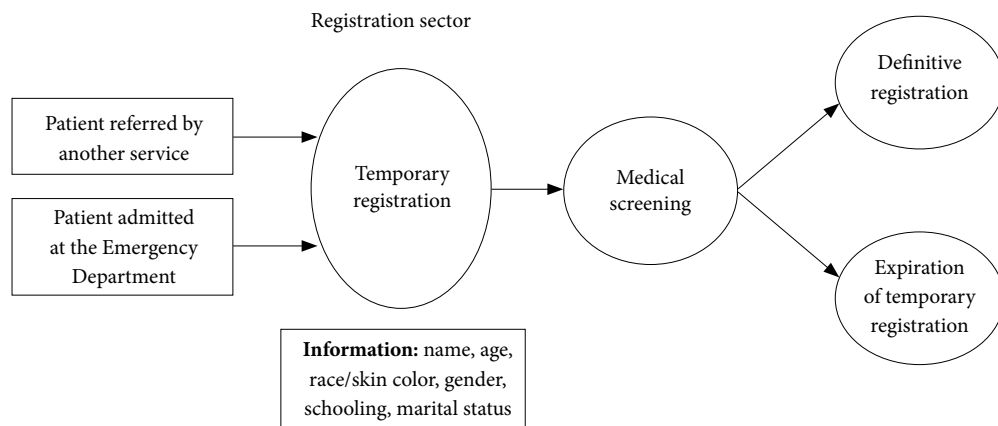
In all registrations, the race/skin color item was completed. Of the 90 valid registrations, in two (2.22%) the race/skin color item was collected by self-declaration and in the rest by heteroidentification (Figure 2). Graph 1 shows the distribution of the filling out of the race/skin color item, with seventy-five (83.3%) of the patients being registered as WHI (white). During observation, the COL (colored) option was not used.

The two occasions in which the race/skin color item was collected by self-declaration oc-

Chart 1. Constructs and ways of adopting the Consolidated Framework for Implementation Research in the study.

Characteristics of the intervention	
Relative advantage	Advantage of implementing the self-declaration-based filling out <i>versus</i> an alternative solution.
Adaptability	How the filling out was adapted, shaped, refined or reinvented to meet local needs.
Internal scenario	
Culture	Norms, values and basic principles of the university hospital
Relative priority	Shared perception among the individuals about the importance of implementing collection norms for the race/skin color item at the university hospital
Available resources	What resources are allocated to the medical archive service? Training, education, physical space and time.
Access to information and knowledge	Easy access to assimilable information and knowledge about the PNSIPN and how to incorporate them into work tasks.
Characteristics of the individuals	
Knowledge and beliefs about the intervention	Individual attitudes towards the filling out and values attributed to the intervention, as well as familiarity with facts, truths and principles related to the intervention.
Other personal traits	Self-declared race/skin color, age, level of schooling and length of service.

Source: Authors.

**Figure 1.** Flow of patient registration at the service, with identification of the moment of collection of the race/skin color item.

Source: Authors.

curred after a discussion of the subject among the employees, motivated by the reading of the informed consent by one of them. On the first occasion, the employee asked the patient what their skin color was, who replied calmly and promptly “black”. The employee then asked whether the patient would like to be registered as “brown” and the patient reaffirmed their race/skin color as black, with information then being

recorded by the employee. After this episode, the same employee repeated the question about skin color to the next patient and promptly recorded the answer, which was “white”, without any questioning. One development that went beyond the observation of the registration itself was that the employee, in a brief dialogue with the researcher, questioned her own self-declaration of skin color and how her daughter had self-declared.

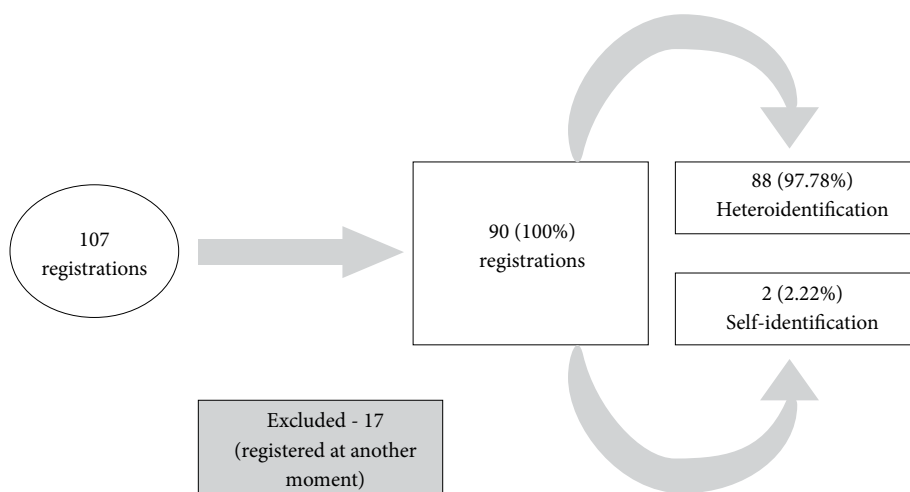
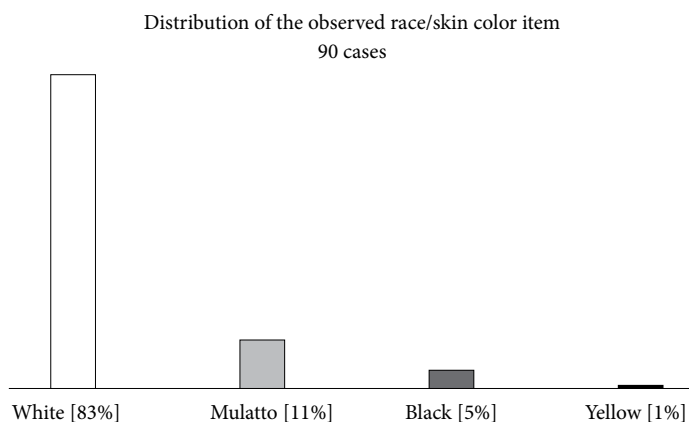


Figure 2. Flowchart on the collection of race/skin color information, carried out between October 2021 and March 2022.

Fonte: Autores.



Graph 1. Distribution of the filling out of the race/skin color item in the 90 observations carried out between October 2021 and March 2022.

Source: Authors.

The field diary also allowed recording situations of interaction between employees and patients about questions related to the electronic patient portal, which was implemented in 2020, containing information about medical consultations and access to laboratory test results. This improvement, instituted through an application, as observed, has the employees' support and involvement.

The outcome of the follow-up, according to the CFIR dimensions used in the study, is described below.

Characteristics of the intervention

The filling out of patient information by the registration sector was adapted based on the need to accelerate care as much as possible, aiming to

avoid waiting lines and delays in screening appointments. The demand for faster care resulted in a reduction in the number of questions that are directly asked to the patient, as emphasized by an employee of the sector “regarding the question of race/skin color, I fill it out according to what is written in the document or else, I check it when filling it out”. As reported by another employee, “the data that are not visible are asked”. In this aspect, during the observations, data related to the level of schooling were asked directly to patients in all cases, with situations of need for clarification due to the answer provided by the patient and options available in the system.

The patient does not have access to the registration information, during or after this procedure, making it impossible for the individual to review or edit their personal data.

Three employees said they knew of a document that standardizes the collection of patient information at the institution but did not mention examples. All six employees answered there was no specific training on how to fill out the race/skin color item. Additionally, there were no audit projects to monitor the method used to fill out the race/skin color item. According to the description of the employees: “The collection has been carried out in the same way for a long time”.

Internal scenario

It is important to mention that the hospital where the research was carried out has a level 2 ONA (National Accreditation Organization) certification. This entity is responsible for the development and management of Brazilian standards of quality and safety in health and classifies as level 2 “institutions that in addition to meeting safety criteria, have integrated management, with processes taking place in a fluid manner and full communication between activities”.

During the research, it was observed that the collection of demographic data from patients is not standardized by the ONA or any other regulatory body, nor does it follow the guidelines of the PNSIPN. The categories gender, occupation, level of schooling and marital status also do not have a collection pattern, with “gender” being mostly decided by the employee’s observation, “occupation” and “level of schooling” by asking a question to the patient and “marital status” by consulting documents or by asking the patient about it.

There is no consensus on the need to implement improvements for the collection of the race/skin color item by employees and managers

of the data collection sector. Of the six employees participating in the survey, none knew about the PNSIPN and four (66%) reported “not knowing” Ordinance n. 344 of the Ministry of Health. Regarding the last document, one employee reported “knowing about it in part” and another preferred not to answer.

Three employees reported that some training was provided at the time they were hired to the sector, more than 30 years before, without further formal training after that.

Characteristics of individuals

The six employees participating in the survey are on average 50.4 years old (SD 10.9), four (66.6%) are women and five (83.3%) are self-declared black. All have finished high school, and two have finished higher education. They have an average of 29.5 years (SD 12.8) working in the service.

Employees identified as a problem the fact that some patients may be offended by the question about self-declaration of race/skin color. Aiming to avoid a potential conflict, employees fill out the race/skin color criterion by heteroidentification.

The situation described above, where an employee had doubts about how the race/skin color item should be collected, the question whether the patient would prefer to be registered as a “brown” even after self-declaring to be black, the employee’s questioning about her own self-declaration and how her daughter declares herself, emerges as an example of the lack of familiarity with the criteria of race/skin color and how individual values can influence the filling out of this item.

Discussion

We structured the discussion of the results from the perspective of the Public Health Critical Race Methodology (PHCR), which is a semi-structured process for conducting research, guided by the principles of the Critical Race Theory, aiming to fight inequities in health. This methodology is based on four main focal points, which dialogue with each other: contemporary patterns of racial relations, knowledge production, conceptualization & measurement, and action. We will especially use the first two focal points³¹.

The observed filling out of the race/skin color item in the service was carried out in all the observations. However, the collection occurred, almost exclusively, by heteroidentification. Ordinance n.

344 of 2017 of the Ministry of Health points out in its first article that “Collecting the skin color item and filling out the field called race/skin color will be mandatory for professionals working in health services, aiming to respect the criterion of the health care user’s self-declaration, within the standards used by the Brazilian Institute of Geography and Statistics (IBGE) and that appear in the forms of the health information systems as white, black, yellow, brown or indigenous.”²⁴. Other studies point out that structural failures such as non-compliance with the ordinance can be understood as a reflection of the structural racism prevailing in society and institutional racism in health^{41,42}. In another study, the employees in charge of collecting the data on race/skin color item claimed, as in this study, that they were afraid of the patients’ reaction when asking for a self-declaration: “But how are we going to say it? What if people are offended? I don’t know, they might not like it, if we ask them about their skin color”, also demonstrating the presence of interpersonal racism impacting the data collection⁴³.

According to the employees’ collection, the prevalence of white patients in this study was 83%. Two studies carried out at the same institution^{44,45}, in patients hospitalized for COVID 19 and among outpatients followed for diabetes, showed a prevalence of white patients of 68% and 79%, respectively, similar to the prevalence of 83% seen in this study. This information is not consistent with the profile of patients treated by SUS, where most of the black population and less than half of the white population are treated¹⁹. These results help us to explain the existing racial relations, seen as an uncomfortable taboo, with a probable tendency towards whitening in the heteroidentification. They demonstrate a common feature of structural racism and the institutional racism in health services, considering that they lead to a difficulty in producing and using reliable data disaggregated by race/skin color to guide decision-making, the definition of priorities and resource allocation, such as previously demonstrated in other studies⁴⁶, a situation that tends to perpetuate inequities.

Focusing on the production of knowledge, conceptualization and measures, the use of CFIR, in addition to providing information about the barriers in the implementation of policies through the analysis of its constructs, can also be evaluated within the PHCR methodology, in an attempt to elucidate the ways in which structural racism interacts with the implementation of equity-oriented interventions⁴⁷.

The three CFIR constructs used in the study helped to identify the negative and positive aspects involved in the implementation of the self-declaration.

The use of an electronic medical record system implemented in the 1990s, in which the previously registered options for the race/skin color item are not consistent with the IBGE criteria, make information accuracy difficult to attain. The need for speed in the recording of information and the impression that the question about race/skin color identification can result in some kind of discomfort gives the impression of an increase in the time spent on its completion. A study on mental health had already mentioned similar impediments to collecting the race/skin color item in basic health⁴⁵, which was also observed in a study with professionals from a Basic Health Unit (BHU), in which they asked, “But we have to explain, mention the options: say that “dark-skinned” is not included and such...”, demonstrating that the collection of this information also brings discomfort to the employees⁴⁸.

Among the observed employees, none knew about the PNSIPN or Ordinance n. 344. The lack of knowledge observed among the employees corroborates data obtained from the general population. In a study published in 2015⁴⁹, 90.5% of the interviewed sample did not know about the PNSIPN and also addresses the stress involving the topic, since 60.9% stated the need for specific policies and 52.7% declared that the PNSIPN tends to reinforce racial discrimination. The lack of adequate training and continuing education in the sector, and the low technical knowledge related to the topic reflects the lack of perception regarding the importance of the topic for health services.

Despite not being the object of this study, the results obtained herein invite the discussion of proposals for possible interventions aiming to reduce the inadequacy of data collection on race/skin color. To understand how information on race/skin color is collected in practice and, in addition, understand the quality of data on race, on which studies by large institutions are based²⁹, allows us to question the impact of small interventions on the production of knowledge that underlies the creation and monitoring of public policies aimed at reducing inequities and improving the health conditions of the black population, which highlights the urgency of actions aimed at changes⁶ and aligns with the fourth focal point of the PHCR methodology: action.

As this study was carried out in a university hospital, with an established culture of concern

for hospital quality demonstrated by adherence to ONA accreditation, we believe it is a fertile ground for improvement interventions. In the present study, the participating employees were mostly self-declared black. Personal experiences on the racial topic as citizens can be a possible starting point for the implementation of measures that may impact on the change in the acquisition of information regarding the race/skin color item. In a recent systematic review, formats and methodologies of interventions for training public health students on racial equity in health⁵⁰ were pointed out.

Among the simple, prompt and potentially high-impact application strategies, we highlight the implementation of educational actions and training activities aimed at employees, combined with the institutional standardization of the race/skin color item collection process, with the adoption of the criteria defined and adopted by IBGE and consequent exclusion of the term “mulatto” from the registration system, and maintenance of the terms “black”, “brown”, “white”, “yellow” and “indigenous”.

In addition to the aforementioned regulations, the PNSIPN and Ordinance n. 344, the São Paulo State Health Secretariat has a Technical Health Committee for the Black Population of the state of São Paulo, one of the first in the country. The State Health Plan for 2020-2023 provides a specific guideline aimed at “promoting comprehensive care for people in their different life cycles, considering the specific segments of the population”. In this document, within the objective of “strengthening the care provided to the Health of Vulnerable Populations”, an Indicator is explicitly mentioned (with a corresponding target) linked to training for health workers on the Health of the Black Population.

Collaborations

RM Geraldo, JC Oliveira and ACCG Germani participated in the conception and design of the study. RM Geraldo, LSC Alexandre, MRA Aguiar, AFS Vieira, JC Oliveira and ACCG Germani were in charge of data analysis and interpretation. RM Geraldo, LSC Alexandre, MRA Aguiar, AFS Vieira, JC Oliveira and ACCG Germani wrote the manuscript, worked on the critical review and approved the final version to be published.

Although it is a small study, with few observations carried out by a single observer, in a challenging context for public health related to the COVID-19 pandemic, it is one of the few studies that goes to the core of the race/skin color data collection in a university hospital and analyzes how data collection is carried out. It is possible to identify in this study aspects of the Public Health Critical Race (PHCR) methodology, in addition to being the first study to analyze the constructs of the intervention implementation using the CFIR in the Brazilian scenario.

As further questions and a basis for future research, it is necessary to evaluate the other domains of the CFIR that were not evaluated in this study, aiming at identifying, through these other domains, other barriers and facilitators of the implementation of self-declaration of race/skin color in health services.

Conclusion

The implementation of the collection of the race/skin color item by mandatory self-declaration, as provided for in the PNSIPN and in Ordinance n. 344/2017 still faces important challenges in the reality of SUS. The use of the Public Health Critical Race (PHCR) methodology and the science of implementation through the CFIR tool showed to be powerful for the systematization of data collection and analysis of the aspects that facilitate and hinder the evaluation and the implementation of the collection of race/skin color information by self-declaration, an essential strategy for the effective implementation of the PNSIPN.

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