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Comparative Analysis of the Constitution and Implementation of Race/Skin Color Field in Health Information Systems: Brazil and South Africa

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Abstract

The inclusion of race/skin color in Health Information Systems makes it possible to measure health inequities. Brazil and South Africa correspond to countries marked by profound inequalities, multiracial constituted that suffered from the historical process of colonization, and had racism legitimized as a structuring model of state development. The objective is to compare the information systems of Brazil and South Africa regarding the configuration and implementation of the item race/skin color. This is a qualitative, descriptive study, based on the content analysis proposed by Bardin. A survey on race/skin color was carried out in health department documents and ministerial sites in both countries. The collected material was processed and analyzed utilizing the IRAMUTEQ R software, version 0.7 alpha 2, with a test $\times 2 > 3.80$ ($p < 0.05$), and by the TABNET application version 4.14 and Excel software, version 2016. In Brazil and Africa South, several health information systems did not include race/skin color. In both countries, health information systems were boosted in the mid-1990s. In Brazil, of the systems that provide data by race/skin color, the inclusion occurred after claims by the black movement. In South Africa, through the creation of the respective systems. The historical configuration of the question of race/skin color in both countries was guided by political and ideological references. In multiracial and unequal countries, race/skin color is a central political category to promote health equity.

Keywords Race and health · Information system · Black population · Brazil · South Africa

Introduction

The term race comprises a sociological and non-biological concept [1], a category based on social markers such as phenotype, ethnicity, and nationality that allows access to particular social resources and power [2]. The term race was originally used by Europeans and has since been restored in an attempt to exceed itself. It means to say, at last, this term is conditioned to the inexistence when the conditions of life and opportunities are defined among the ethnic-racial contingents [3]. Recent information suggests race portrays more than socioeconomic inequality [4]; it involves historical legacies of discrimination and social inequity [5]. For social scientists, scientifically, race does not exist. However, from a political and social viewpoint, using the term, race, is justified as a category of domination and exclusion. The use of race/skin color as an analytical tool for social stratification translates the centrality of fragmentation in Western societies [5].

The use of the race/skin color field brings the possibility of portraying inequalities in health in the public health

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section [6]. Identifying morbidity and mortality patterns in ethnic-racial groups provides evidence of disparity, omission, difficulty in access, and institutional racism in the health services. Thus, its strategic sense is immeasurable in evaluating the quality of healthcare [7]. Not alone socioeconomic factors, but also the perseverance of ethnic or racial inequalities, have guided studies on the effects of racism on health and evidenced it as a determinant of health [8]. Studies involving morbidity and mortality profiles often resort to the categorization of social groups to understand how health disparities are instituted and reproduced [5]. In contexts of significant inequalities, using the race/skin color field in information systems consists of a theoretical and practical necessity to implement policies aimed at decreasing health inequalities [9].

The information obtained from the inclusion of race/skin color field in the health information system (HIS) in the different countries becomes mandatory for creating, implementing, and sustaining policies aimed at ethno-racial groups [10]. In Brazil, creating affirmative policies, because of pressure from social movements, especially the black movement, seems to have influenced the racial identity of the population since 2003. Given that from the 2010 census, there was a significant increase in how many people declared themselves black [11]. According to a census survey conducted by the United Nations Organization (UNO) Statistics Division, between 1990 and 2000, in only 27 (22%) of the 121 countries and territories investigated, information was found to disaggregate national data according to those from ethnicity/race/physical appearance/continental ancestry [7].

In the present international context, in- or exclusion of the ethno-racial variable in information systems is conditioned to the purpose of the survey, its specific use, the legal, political and axiological dimensions adopted by national states, and their civil society institutions [7]. In multiracial societies such as Brazil and South Africa, the registration of the race/skin color variable in HIS has capital importance in the constitutional process of securing rights, promoting historical reparation, and the generation of policies anchored in equity.

Brazil and South Africa are two developing countries, socially complex, with distinct historic-cultural formation, a similar economic profile, characterized by marked social inequality and the adoption of opposed racial policy [12]. Socioeconomically, Brazil and South Africa are considered two of the most unequal countries in the world.

Brazil has 211.414.617 million inhabitants, of which 45.2% declared themselves white, 45.1% brown, 8.9% black, 0.5% yellow, and 0.4% indigenous [13]. The black and brown race/color population segments together represent 53.92% of the total population. Thus, Brazil has the largest concentration of black populations outside Africa and is the only capitalist country in Latin America that has assumed a universal public health system that assists more than 200 million people [14]. The Brazilian unified health system is very complex, and its consolidation in a heterogeneous, iniquitous country with historical structural problems is a great challenge [15].

In turn, South Africa has an estimated population of 57.7 million, with approximately 46.7 million blacks (81% of the population), 4.5 million whites, 5.1 million Coloreds, and 1.4 million Indians/Asians [16]. South Africa's health system faces many problems, such as fragmentation in different sectors, vast inequalities, and racial and gender discrimination, which go back to Apartheid (1948–1993). The public health system remains underfunded, while the private system accounts for 55–60% of total health spending and only serves 15% of the population [17]. The health situation, health policies, and services have been profoundly affected by South Africa's segregationist history [18].

In Brazil, racial classification is phenotypically defined precisely by skin color and is, therefore, conceptualized as brand prejudiced, based on racial appearance, a reformulation of color prejudice [19]. Skin color is considered the most important and most used criterion in almost all racial classifications in the Brazilian context [20]. In South Africa, a multiracial and ethnic nation, racism is based on discriminatory treatment according to national origin or ethnicity [21]. In the current Brazilian census, the term color/race is used, while in South Africa, the term race is applied. As this is an investigation that considers the official ethnic/racial classification of both countries, the term race/skin color was adopted.

Racial classification based on people's race/skin color was inspired by racial segregation practiced in both countries. In fact, policies based on exclusionary racial laws, although practiced at different times, were similar in many respects in Brazil and South Africa. In this context, the Native Urban Act (1923) and in Brazil, Law Decree 3688/41, which limited the access of blacks and other ethnic groups in areas considered white, are highlighted. In the educational sphere, the provincial laws of 1837 prohibited the enslaved and free or freed blacks from attending Brazilian public school [22].

In Brazil, health inequities affect the black population [23]. These inequities are expressed in early death, high maternal and child mortality rates, high prevalence of chronic, and infectious morbidities, along with high rates of violence [24]. In South Africa, inequalities between blacks and whites in the current political system are extensive, and the rights and interests of ethnic minorities and other minorities are not assured [25]. From this perspective, considering the importance of race/color in the HIS, the historical, political, economic, health, and social structure of multiracial and highly unequal nations such as Brazil and South Africa, is the focus of this study. Therefore, we aim to compare the HIS of these two countries concerning the constitution and implementation of the race/skin color field.

Methods

Study Design

Exploratory, descriptive research, with a qualitative approach, is based on the categorical thematic content analysis proposed by Bardin [26]. In this study, the analysis was based on documents from the national health departments of Brazil and South Africa. In the pre-analysis, a survey and organization of documents were carried out. In the second phase, coding and categorization were developed based on the statistical analysis processed by the software, IRAMUTEQ R (Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires), version 0.7 alpha 2. The third phase comprised an inferential interpretation of the corpus and thematic categorization. The corpus, textual content of the documents, was submitted to the classical lexicographic analysis utilizing the Descending Hierarchical Classification (CDC) and cloud. Representatives were used, such as words with $x^2 > 3.80$ ($p < 0.05$). Subsequently, a survey was conducted at the Department of Informatics of Brazil (DATASUS) and the National Health Department of South Africa. The following information was collected, name of the HIS, the purpose of the HIS, year of creation, the status of the HIS (active/inactive), presence or absence of race/skin color, and year of inclusion of race/skin color. Data collection and analysis were performed using the TABNET version 4.14 application and Excel software version 2016. The findings are presented in the systematic table.

Health Information System in Brazil

In Brazil, the Department of Informatics of Unified Health System (DATASUS), an organ of the Executive Secretary of the Ministry of Health, is responsible for operating, collecting, processing and storing large databases, and disseminating information on health. In Brazil, the HIS in the DATASUS uses the color/race criteria adopted by the IBGE of 1991: white, black, brown, yellow, and indigenous, of which black and brown aggregates formed the black category. All epidemiological and assistance information systems of the DATASUS were intended.

Health Information Systems in South Africa

The largest information system in force, in South Africa, is the District HIS (DHIS). The DHIS v1, a free and open-source software, has been translated into many languages and being introduced in many countries. The HIS program (HISP) was developed to improve the quality and reliability of the data, improve the use of managerial information, save resources, and improve the management of health services. In addition to the DHIS, the National Department of Health, through HISP, obtained data and implemented the main HIS post-Apartheid. The South African HIS uses four official racial categories, black, Colored, White, and Asian/Indian. From the miscegenation between whites, enslaved blacks, San and the Khoikhoi indigenous groups are the so-called Colored [27].

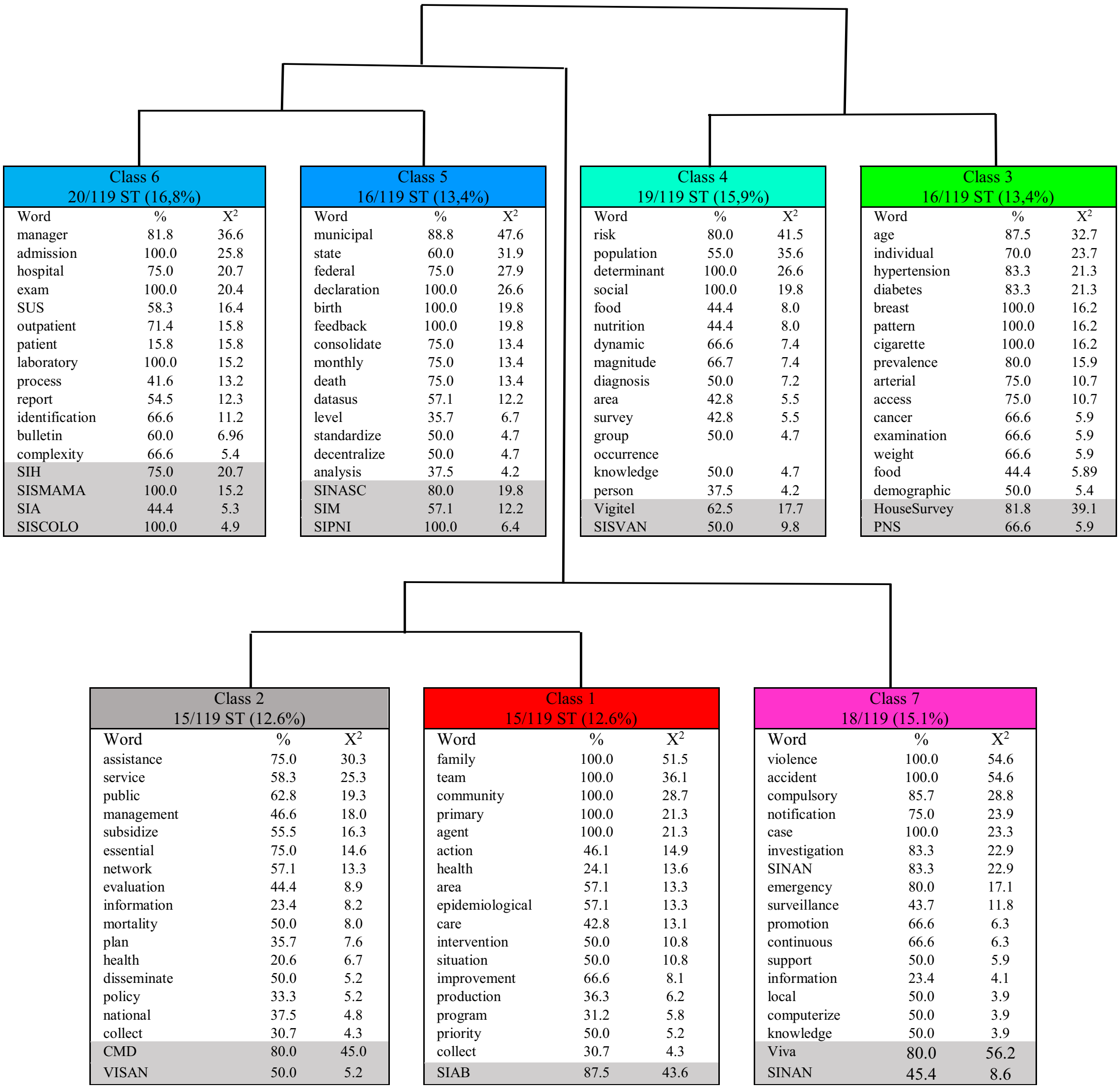
Results and Discussion

The corpus of Brazil's HIS includes 18 texts, separated into 144 text segments (TS), and with the use of 119 (82.64%) TS, 5325 occurrences emerged, of which 608 had a single frequency. The analyzed content was categorized into seven classes, presented in a hierarchical scheme, with a list of frequency of words in each class, and the characteristics that stood out the generated from the chi-square test (Fig. 1).

In the dendrogram, the class 6 category "Information and Assistance" includes the production of data at the outpatient and hospital assistance level. In this context, data collection in the Unified Health System makes it possible to identify the patient's condition and care needs and produce bulletins and reports at various levels of technological density. In this class, the Hospital Information System, Ambulatory Information System, Breast and Cancer Information System and the Cervical Cancer Information System stand out. In a related way, in class 5 category "Information Systems and Vital Records", the production, consolidation, and analysis of data on birth, mortality, and immunization by the Department of Information of the Unified Health System stands out as a tool to support the planning and the evaluation of policies, programs, and interventions in the various spheres of public health management.

Class 4 category "Information Systems and Social Epidemiology" highlights the dimension of HIS in Brazil. It gathers epidemiological information, analyzes risk behaviors, and nutritional problems. Furthermore, it identifies the social determinants of health, vulnerable groups, and high prevalence morbidities such as hypertension, diabetes, and non-communicable diseases at the individual and population level. Class 3 category, "Information and Governance" has a close relationship with class 4, and points to the importance of national research in raising individual characteristics as a strategy to measure the prevalence of morbidities in the population and to qualify access to health actions and services.

Class 2 category "Information System, Management and Public Policies" includes HIS as an essential subsidy for the management, planning, development, and implementation of public policies. In this sense, class 1 category "Information System and Primary Care" comprises the dimension of collecting data from individuals, families, and communities, characterizing the epidemiological situation of a given geographical area, producing indicators,



Class 6
20/119 ST (16,8%)

Word	%	X^2
manager	81.8	36.6
admission	100.0	25.8
hospital	75.0	20.7
exam	100.0	20.4
SUS	58.3	16.4
outpatient	71.4	15.8
patient	15.8	15.8
laboratory	100.0	15.2
process	41.6	13.2
report	54.5	12.3
identification	66.6	11.2
bulletin	60.0	6.96
complexity	66.6	5.4
SIH	75.0	20.7
SISMAMA	100.0	15.2
SIA	44.4	5.3
SISCOLO	100.0	4.9

Class 5
16/119 ST (13,4%)

Word	%	X^2
municipal	88.8	47.6
state	60.0	31.9
federal	75.0	27.9
declaration	100.0	26.6
birth	100.0	19.8
feedback	100.0	19.8
consolidate	75.0	13.4
monthly	75.0	13.4
death	75.0	13.4
datasus	57.1	12.2
level	35.7	6.7
standardize	50.0	4.7
decentralize	50.0	4.7
analysis	37.5	4.2
SINASC	80.0	19.8
SIM	57.1	12.2
SIPNI	100.0	6.4

Class 4
19/119 ST (15,9%)

Word	%	X^2
risk	80.0	41.5
population	55.0	35.6
determinant	100.0	26.6
social	100.0	19.8
food	44.4	8.0
nutrition	44.4	8.0
dynamic	66.6	7.4
magnitude	66.7	7.4
diagnosis	50.0	7.2
area	42.8	5.5
survey	42.8	5.5
group	50.0	4.7
occurrence		
knowledge	50.0	4.7
person	37.5	4.2
Vigitel	62.5	17.7
SISVAN	50.0	9.8

Class 3
16/119 ST (13,4%)

Word	%	X^2
age	87.5	32.7
individual	70.0	23.7
hypertension	83.3	21.3
diabetes	83.3	21.3
breast	100.0	16.2
pattern	100.0	16.2
cigarette	100.0	16.2
prevalence	80.0	15.9
arterial	75.0	10.7
access	75.0	10.7
cancer	66.6	5.9
examination	66.6	5.9
weight	66.6	5.9
food	44.4	5.89
demographic	50.0	5.4
HouseSurvey	81.8	39.1
PNS	66.6	5.9

Class 2
15/119 ST (12.6%)

Word	%	X^2
assistance	75.0	30.3
service	58.3	25.3
public	62.8	19.3
management	46.6	18.0
subsidize	55.5	16.3
essential	75.0	14.6
network	57.1	13.3
evaluation	44.4	8.9
information	23.4	8.2
mortality	50.0	8.0
plan	35.7	7.6
health	20.6	6.7
disseminate	50.0	5.2
policy	33.3	5.2
national	37.5	4.8
collect	30.7	4.3
CMD	80.0	45.0
VISAN	50.0	5.2

Class 1
15/119 ST (12.6%)

Word	%	X^2
family	100.0	51.5
team	100.0	36.1
community	100.0	28.7
primary	100.0	21.3
agent	100.0	21.3
action	46.1	14.9
health	24.1	13.6
area	57.1	13.3
epidemiological	57.1	13.3
care	42.8	13.1
intervention	50.0	10.8
situation	50.0	10.8
improvement	66.6	8.1
production	36.3	6.2
program	31.2	5.8
priority	50.0	5.2
collect	30.7	4.3
SIAB	87.5	43.6

Class 7
18/119 (15.1%)

Word	%	X^2
violence	100.0	54.6
accident	100.0	54.6
compulsory	85.7	28.8
notification	75.0	23.9
case	100.0	23.3
investigation	83.3	22.9
SINAN	83.3	22.9
emergency	80.0	17.1
surveillance	43.7	11.8
promotion	66.6	6.3
continuous	66.6	6.3
support	50.0	5.9
information	23.4	4.1
local	50.0	3.9
computerize	50.0	3.9
knowledge	50.0	3.9
Viva	80.0	56.2
SINAN	45.4	8.6

Fig. 1 Dendrogram of descending hierarchical classification of health information systems in Brazil. Source: the authors, 2020

prioritizing actions, and promoting improvements in the scope of primary care.

Class 7 category "Health Surveillance and Information" highlights the systematic, continuous, and decentralized use of information for the investigation of compulsory notification diseases and conditions, violence, accidents, and emergencies. Thus, it defines preventive measures, intervention priorities, and assesses the impact of actions. In this class, the Violence and Accident Surveillance systems (VIVA) and the Notifiable Diseases Information System (SINAN) emerged.

In Brazil, HIS, whether for assistance or epidemiological purpose, is fundamental for program management, improving the quality of services, surveillance of diseases and conditions, and strategic use of information. Brazil's HIS is diverse, with a wide scope, specific objectives, and functionalities. The word cloud (Fig. 2) makes it possible to highlight the most frequent words related to the HIS in the Brazilian context.

From the word cloud, "health," "information," "system," "data," "program," "population," "assistance," and "Unified Health System (UHS)" stood out. Thus, Brazil's HIS allows epidemiological diagnosis of the Brazilian population, identifying the determinants of health, subsidizing activities of management, planning, programming, monitoring, and evaluation of health policies. Furthermore, it strengthens care networks and activities, directs the allocation of resources and health financing, and hence, contributes to implementing the principles and guidelines of the Unified Health System. The race/skin color variable did not emerge in the analysis.

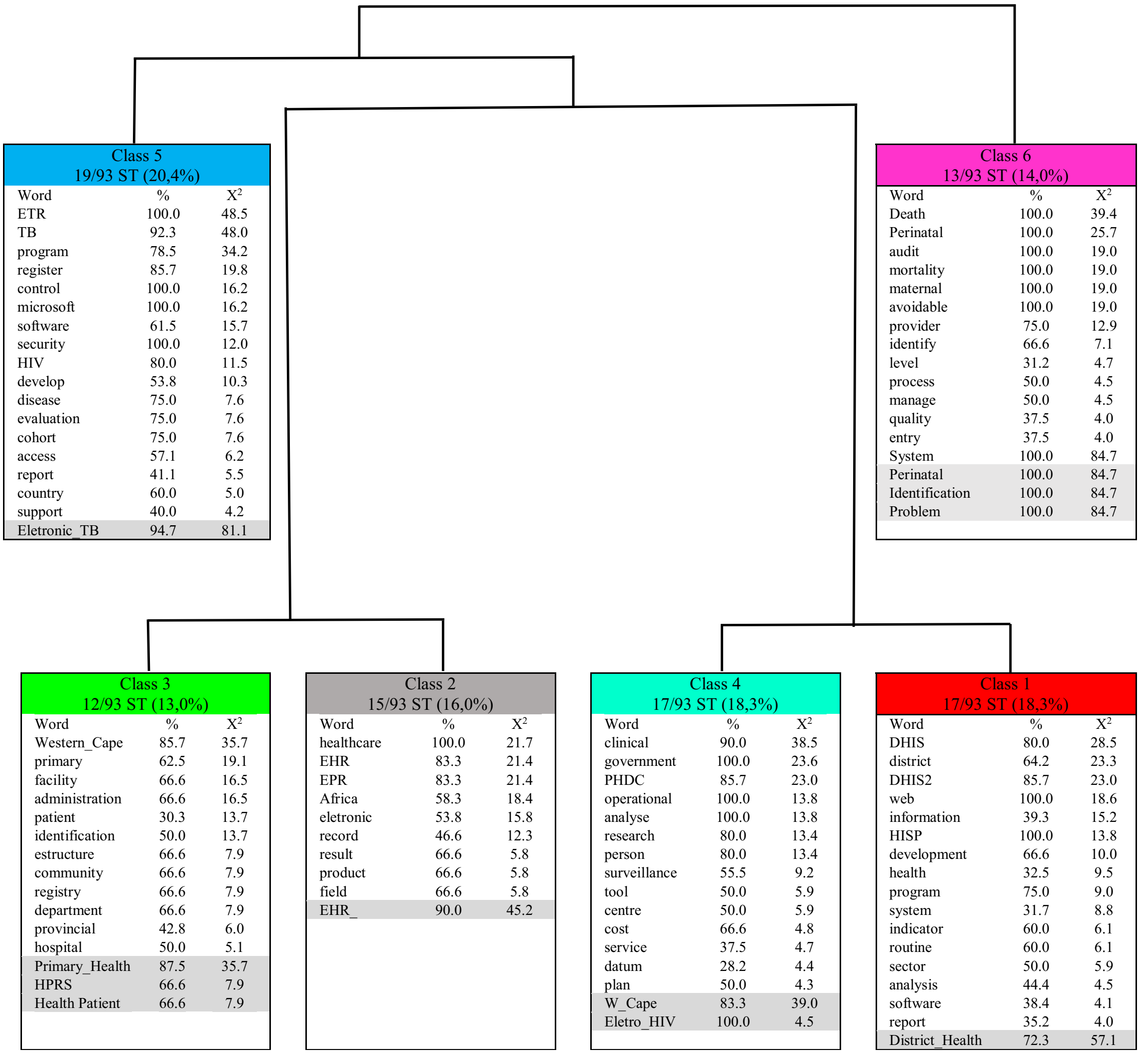
The corpus related to the HIS of South Africa comprised ten texts, separated into 114 TS, with 93 (81.5%) TS used, 4132 occurrences emerged, of which 721 had a single frequency. The analyzed content was categorized into seven classes (Fig. 3).

Fig. 2 Word cloud of the Brazilian health information system. Source: the authors, 2020

In class 6, the category "Information System and Maternal and Perinatal Care" highlights the Perinatal Problem Identification Program (PPIP), a system developed to assess the quality of perinatal care through the audit of perinatal and maternal deaths. In this regard, it makes it possible to identify determinants and preventable factors, manage and provide care, and improve the quality of maternal and perinatal care.

Class 5 category "Information for Action," stands out as an important tool for tuberculosis/HIV surveillance in the country. Continuously capturing data enables producing reports, planning actions, monitoring the evolution, and evaluating programs aimed at coping with the high levels of tuberculosis/HIV.

In class 3, the category "Information Technology and Health Management," the Health Patient Registration System stands out, which provides patient registration using a South African identification number. The Primary Health Care Information System a provincial database, implemented in the community centers of the Western Cape also allows an



Class 5
19/93 ST (20,4%)

Word	%	X^2
ETR	100.0	48.5
TB	92.3	48.0
program	78.5	34.2
register	85.7	19.8
control	100.0	16.2
microsoft	100.0	16.2
software	61.5	15.7
security	100.0	12.0
HIV	80.0	11.5
develop	53.8	10.3
disease	75.0	7.6
evaluation	75.0	7.6
cohort	75.0	7.6
access	57.1	6.2
report	41.1	5.5
country	60.0	5.0
support	40.0	4.2
Eletronic_TB	94.7	81.1

Class 6
13/93 ST (14,0%)

Word	%	X^2
Death	100.0	39.4
Perinatal	100.0	25.7
audit	100.0	19.0
mortality	100.0	19.0
maternal	100.0	19.0
avoidable	100.0	19.0
provider	75.0	12.9
identify	66.6	7.1
level	31.2	4.7
process	50.0	4.5
manage	50.0	4.5
quality	37.5	4.0
entry	37.5	4.0
System	100.0	84.7
Perinatal	100.0	84.7
Identification	100.0	84.7
Problem	100.0	84.7

Class 3
12/93 ST (13,0%)

Word	%	X^2
Western_Cape	85.7	35.7
primary	62.5	19.1
facility	66.6	16.5
administration	66.6	16.5
patient	30.3	13.7
identification	50.0	13.7
estructure	66.6	7.9
community	66.6	7.9
registry	66.6	7.9
department	66.6	7.9
provincial	42.8	6.0
hospital	50.0	5.1
Primary_Health	87.5	35.7
HPRS	66.6	7.9
Health Patient	66.6	7.9

Class 2
15/93 ST (16,0%)

Word	%	X^2
healthcare	100.0	21.7
EHR	83.3	21.4
EPR	83.3	21.4
Africa	58.3	18.4
eletronic	53.8	15.8
record	46.6	12.3
result	66.6	5.8
product	66.6	5.8
field	66.6	5.8
EHR_	90.0	45.2

Class 4
17/93 ST (18,3%)

Word	%	X^2
clinical	90.0	38.5
government	100.0	23.6
PHDC	85.7	23.0
operational	100.0	13.8
analyse	100.0	13.8
research	80.0	13.4
person	80.0	13.4
surveillance	55.5	9.2
tool	50.0	5.9
centre	50.0	5.9
cost	66.6	4.8
service	37.5	4.7
datum	28.2	4.4
plan	50.0	4.3
W_Cape	83.3	39.0
Eletro_HIV	100.0	4.5

Class 1
17/93 ST (18,3%)

Word	%	X^2
DHIS	80.0	28.5
district	64.2	23.3
DHIS2	85.7	23.0
web	100.0	18.6
information	39.3	15.2
HISP	100.0	13.8
development	66.6	10.0
health	32.5	9.5
program	75.0	9.0
system	31.7	8.8
indicator	60.0	6.1
routine	60.0	6.1
sector	50.0	5.9
analysis	44.4	4.5
software	38.4	4.1
report	35.2	4.0
District_Health	72.3	57.1

Fig. 3 Dendrogram of descending hierarchical classification of health information systems in South Africa. Source: the authors, 2020

identification number for each patient who accesses the service, enabling the best clinical and operational management of care. In class 2, the category "Information Technology and Health Care," the electronic record of patient history for care management in the country stood out, for example, Electronic Health Records and Electronic Patient Records (EPR).

Class 4, category "Information management and health care," observes the Western Cape Province Health Data Center, which consolidates clinical patient data in government services, identifies assistance needs for interventions, and supports research through operational and epidemiological analysis. Class 1, category "Information and Public Health System" highlights the DHIS, which is an electronic system of national scope. From the captured and stored routine data, it produces a high volume of information for planning health services management, statistical analysis, indicators, decision making, and government actions. In this dimension, the DHIS2 version of the DHIS was launched to improve the production of patient data, map health status, and strengthen health surveillance and management.

Aggregate data provide reports, guide organizational aspects, operational procedures, norms and standards, influence health planning, epidemiology, surveillance and research, impact service provision, and support continuity and quality of care. Furthermore, investing in information technology is also a strategic function that makes up South African HISs. The race/skin color variable did not emerge in the analysis. As shown in the word cloud (Fig. 4), "data," "health," "system," "patient," "information," "assistance," "record," "software," "report," "electronic," and "support" were the most prevalent words in the South African HIS corpus.

Fig. 4 Word cloud of the South Africa health information systems. Source: the authors, 2020

The HISs of both countries are supported by specific legislation that underlies the principles, objectives, functionalities, the development, implementation, and use of information at all levels of their health systems. In Brazil, the race/skin color variable is mentioned once in the HIS corpus alongside individual characteristics, such as gender and age. Given the low textual occurrence, this race/skin color variable did not emerge in the analysis.

In the mid-90s, when the Unified Health System was established in Brazil, and towards the end of Apartheid in South Africa, the HISs were fully developed and boosted. In the sequential analysis, it was observed that Brazil had a substantially higher volume of HISs, and many included race/skin color field. In contrast, no information on race/skin color existed in operational and important systems such as the Outpatient Information System, National Immunization Program Information System, Primary Care Information System (Family Registration), Registration System and hypertensive and diabetic follow-up, Cancer Information System (cervix and breast), and the Supplementary Health Information: Beneficiaries, UHS beneficiary care (Table 1).

In Brazil, the production of data in the HIS is of a continuous, periodic, or occasional nature. In many information systems, that on race/skin color field is not available, despite the mandatory effect in Brazilian legislation. The inclusion of the race/color occurred a few years after introducing the system so that many epidemiological and care information was produced without data analysis by race/skin color. Some of the established systems were inactive, and data collection did not include the race/skin color field.

In South Africa, there are several HISs (Table 2). The country has nine provinces that use different health systems, including several hospitals using different ones. However, many of these systems overlap or are similar. Not all provinces have the National Health Management Information System. Electronic Medical Records systems, for example, operate in only a third of the provincial hospitals. Systems segmentation is one of the problems also faced by the private sector [28]. Fragmentation of the HIS and a lack of interoperability correspond to the main problems in South Africa's health system [29]. In Brazil, integration among the most diverse subsystems remains a challenge. Also, the lack of integration between subsystems remains on the agenda of countries around the world [30].

In South Africa, the race/skin color field is not included in all HISs. The first post-Apartheid HIS deployed was the DHIS in 1996, which aimed to develop a sustainable, effective system capable of creating a core dataset, improving the coverage and quality of local healthcare. Though the race/skin color field was not included, a lack was also observed in other important HISs, such as the Electronic HIV and TB Registers, and the Electronic Patient Management System. Most of the systems that do include the race/skin color field denote sociodemographic recorded data.

Table 1 Characterization of the health information systems and the inclusion of race/skin color field, in Brazil, 2019

Health information system (HIS)	HIS objective	Year established	Status of HIS (active/inactive)	Race/skin color field: yes or no	Year of inclusion of race/skin color field
	Health information systems—epidemiology				
Mortality information system (SIM)	To report data on deaths	1979	Active	Yes	1996
Information system on live births (SINASC)	To register birth data	1994	Active	Yes	1996
Information system on notifiable diseases (SINAN)	To register cases of diseases and diseases of compulsory notification	2001	Active	Yes	2001
National Health Survey - 2013	To register data about access, services, continuity of care, and the health conditions of the population, the surveillance of non-communicable chronic diseases and the associated risk factors	2013	2013	Yes	2013
	Health information systems—healthcare				
Hospital information system (SIH)	To register the care from UHS-funded hospitalizations	1984	Active	Yes	2008
Outpatient information system	To register outpatient care, procedures and treatments	2008	Active	No	–
Information System of the National Immunization Program	To register vaccination information	1994	Active	No	–
Primary Care Information System-Family Registration	To register and monitor actions carried out by Family Health Strategy teams	1998	Active	No	–
Food and Nutrition Surveillance—users of primary care	To register and monitor the nutrition and food conditions of the population	2000–2007	Inactive	Yes	2000
Food and Nutrition Surveillance—nutritional status of beneficiaries of the Bolsa Família Program	To register and monitor the nutritional conditions of Bolsa Familia users	2006–2008	Inactive	No	–
Minimum data set	To register data from all health facilities in the country at each care contact	2017	Active	Yes	2017
Nutritional status (SISVAN)	To register and monitor the nutritional status of the population	2006–2008	Inactive	No	–
System of registration and follow-up of hypertensive and diabetic patients (HIPERDIA)	To register and follow-up the population with hypertension and/or diabetes mellitus attended at the outpatient network of the UHS	2002–2013	Available data until 2013	No	–
Cervical Cancer Information System (SISCOLO) Cervico-Vaginal Cytopathological Examination and Microflora Anatomical Pathological Examination of the Cervix Breast Cancer Information System (SISMAMA) MAMA Cytopathological Examination MAMA Histopathological Examination Mammography Exam	To register and process patient identification information and cytopathological and histopathological examination reports	2000–2006 2006–2015 2009–2015 2009–2015 2009–2015	Inactive Inactive Inactive Inactive Inactive	No Yes Yes Yes Yes	– 2007 2009 2009 2009
Cancer Information System - SISCAN (cervical and breast)	To register data on suspicion and diagnostic confirmation, on diagnostic and therapeutic approaches to cervical cancer screening and positive breast cancer / changed	2013	Active	No	–
VIGITEL - Surveillance of Risk and protective factors for chronic diseases through telephone survey	To register and monitor factors related to the main determinants of chronic diseases are not (DCNT) via telephone survey	2006 2007 2008 2009 2010	– – – – –	No No No No No	– – – – –
Surveillance of violence and accidents (VIVA)	To generate information about violence and accidents	2006 2007 2009 2011	– – – –	Yes Yes Yes Yes	– – – –
A household survey of risk factors for non-communicable diseases and disorders—2002/2003	To register and estimate the magnitude of exposure to behavior and risk factors for diseases and non-communicable diseases (DANT), access to early cancer screening of breast and cervix and selected diseases (reported morbidity)	2002–2003	–	No	–
Dental Health Surveys—1996	To register data regarding dental caries, periodontal disease and prosthesis needs	1996	–	No	–
A national survey of prevalence of schistosomiasis and Geo-Helmintoses 2011/2015	To register and estimate the prevalence of schistosomiasis mansoni and geohelminthesis	2011	–	No	–
Additional Health information: Beneficiaries Visits to beneficiaries in the UHS	To register master data from beneficiaries of private health care plan operators	2000–2019 2001–2017	Active –	No No	– –

Source: Department of Informatics of Unified Health System (UHS), Ministry of Health, Brazil

Comparatively, South Africa has the lowest number of epidemiological HISs containing the race/skin color field. Systems that do incorporate race/skin color fields occurred concurrently on the creation date of the respective HIS's. Conversely, in Brazil, the insertion of the race/color field in the various systems occurred after demands made by the black movement, other social movements, researchers, intellectuals, and specialists. The black movement defended this insertion vehemently as an important political strategy for monitoring health inequalities and implementing public policies in the country. In this sense, the National Comprehensive Health Policy for the Black Population has been made official in Brazil since 2009. Among the guidelines is advocating for the inclusion of "color" in all data collection instruments, which include public services, affiliated, or contracted by the Unified Health System. Also, improving the quality of HIS related to processing and analyzing data disaggregated by race, color, and ethnicity [24]. South Africa does not have a specific policy for this purpose.

The Ethnic/Racial Classification and the Health Information Systems of Brazil

The inclusion of race/skin color field in Brazil's official statistics corresponds to a historical claim of the black movement. The theory of racial democracy linked to the claim that the inclusion of race or skin color in the information systems represented a discriminatory measure, culminated in the absence of epidemiological information about these attributes of the individuals. The obtained data were considered fundamental by social scientists and activists of the black movement to alleviate the discourse of Racial Democracy [10].

In the field of epidemiology, the race/skin color field for many years was absent from the debates and official texts. However, from 1990 onwards, significant advances are recorded in the public sphere. Among these, the introduction of the race/skin color field in the HIS is highlighted [31]. During this period, the agenda focused on the health of the black population was elaborated, and the association of epidemiological data linked to race, color, and ethnicity attested to the existence of inequities and injustice in health that affect the black population [23].

Throughout the twentieth century, color acquired maximum expression in the discussions about culture and ethnicity in the country, whose official classification pattern titled Brazil as a "Rainbow Nation" that is to say, an inclusive and harmonious nation. The policy stimulated selective miscegenation. The immigration of people, considered racial and ethnically superior, implemented in the late nineteenth century, represented the most prominent lever of the Brazil Nation project. In practical terms, the metaphor of the rainbow nation comprised a rhetorical political strategy aimed at mitigating conflicts, valuing the differences between the social groups without considering the systemic inequalities.

In Brazil, the ethnic-racial classification has undergone semantic transformations, inclusions, exclusions, and substitutions motivated by the dynamics of ethnic-racial relations. The first nationwide census in 1872, used the term race with the following records, white, black, brown, and cabocla (indigenous). The category qualified the enslaved or descending population of enslaving [32]. In the 1890 census, the term pardo was replaced by mestizo [33].

In the 1900 and 1920 censuses, the race criterion was excluded because of tensions regarding the half-breed classification and inability to capture ethnic-racial diversity of Brazilians and reintroduced in the national 1940 census [33]. Likewise, in the 1970 census, the period of the military dictatorship in Brazil and the denial of profound racial inequalities, the brown category was again excluded and reintroduced in the 1980 census [34]. Thus, there was no collection of the color field in the censuses of 1900, 1920, and 1970.

In 1910 and 1930, no censuses were performed in Brazil. Motivated by the inaccuracy in the classification and resistance of the so-called mestizos, the race category was suppressed, although they self-classified themselves as such [35]. In 1940, they introduced the category color and the classifications white, black, and yellow (motivated by Japanese immigration boosted between 1908 and 1930), whose recommendation was to record a trace in any other definition of the respondent. A posteriori, the trait received the codification of the brown category, including the Indians.

In the 1950 and 1960 censuses, the brown category was included. Thus, the color category was set to "white, black, brown and yellow" [34]. Until 1990, the official categories of the classification system were based on color. It is worth noting that color corresponds to physical appearance, not to racial origin, although in Brazil, color results from the mixture of the three races, European, African, and Indian [36]. In the 1991 census, the indigenous category was inserted through the political, symbolic, and ideological struggle of the indigenous movement.

The introduction of the race/skin color field in the HIS occurred in 1996. Initially, it was incorporated into the national system of live births (SINASC) and the Mortality Information System (SIM) and, in 2001, in the SINAN. In Brazil, the inclusion of the race/skin color field in the HIS is the result of a long political trajectory from the black movement imposing a response from the Brazilian State. From this trajectory, we highlight the creation of the Inter-ministerial Working Group for the appreciation of the black population in 1995. The main contribution of the task group was to introduce race/color in the SIM and SINASC, and institute resolution 196/96 of the National Health Council, along with establishing the National Policy of Integral Health of the Black Population in 2009 [24]. The resolution outlines the mandate

Table 2 Characterization of the Health Information Systems and the inclusion of the race/skin color field, South Africa, 2019

Health information system (HIS)	HIS objective	Year established	Status of HIS (active/inactive)	Race/skin color: yes or no	Year of inclusion of the race/skin color
	Health information systems—epidemiology				
District Health Information System (DHIS)	To provide for data entry, report generation, and analysis of data routinely collected in all public health units.	1996	Active	No	–
Electronic Tuberculosis Register	To register data for tuberculosis monitoring	1995	Active	No	–
Electronic HIV Register—Electronic Patient Management System (EPMS)	To register data for HIV surveillance and monitoring	2010	Active	No	–
	Health information systems—healthcare				
Electronic Health Records (EHR) Electronic Patient Record	To record data from multiple healthcare providers and store it in a single record, providing a complete record key elements of an individual's health history	2002	Active	Yes	2002
Electronic Drug-resistant Tuberculosis Register- EDRWeb	To register and manage treatment of drug-resistant tuberculosis patients	2007	Active	Yes	2007
Standard Information Jointly Assembled by Networked Infrastructure (DHIS equivalent)—Only Western Cape	To register and aggregate information, feed the District Health Information System (DHIS) as well as collect discrete patient-level data such as maternal mortality data	2000	Active	No	2000
Perinatal Problem Identification System—PPIP	To register adverse perinatal outcomes	2000	Active	Yes	2000
Clinicom hospital information system (Only Western Cape)	To register patient demographics and hospital administrative data	1994	Active	Yes	1994
Primary Health Care Information System—PHCIS (Only Western Cape)	Used for patient management and routine information and disease records for HIV and tuberculosis	2007	Active	No	2007
Patient Registration and Health Management Information System—PREHMIS (Cape Town)	To register administration and routine data collection in the 82 City of Cape Town primary care clinics	2015	Active	No	2015
Health Patient Registration System (HPRS)	To register and allocate a unique patient ID number for all patients assisted in the public health sector	2013	Active	Yes	2013
Western Cape Provincial Health Data Centre	Consolidates person-level clinical data across government services, leveraging sustained investments in-patient registration systems, a unique identifier, and maturation of administrative and clinical digital health systems	2018	Active	Yes	2018
Disease Management—TIER.Net	To register and monitor HIV treatment	2001	Active	Yes	2001

Source: National Department of Health, South Africa

to include race/skin color in all research involving human beings [24].

Ethnic/Racial Classification and the Health Information Systems in South Africa

The racial classification system adopted in South Africa was the subject of much discussion. Instituting a national system of vital statistics was shaped by geopolitical forces and segregationist laws marked by discrimination. Initially, discrimination was based on the geographical location, given the exclusion of those who lived in rural areas, and later on the racial composition [37].

For the first census in 1798, all Cape Colony family heads had to provide information about household members along with the number of enslaved people on their premises and the livestock they owned [38]. In 1823, the first South African statistical report, entitled The Annual Blue Book in the Cape of Good Hope, was released and continued until 1837 [38].

Before 1910, birth and death data were decentralized, and laws differed in each colony [37]. Chronologically, in the Cape censuses including all races were carried out in 1865 and 1875, and in two other provinces, the Free State and Natal, in 1880 and 1891, respectively [38]. In the Transvaal province, in the first census carried out in 1890, only the white population was included. Censuses covering the entire country took place in the Cape, Natal, the Free State, and Transvaal in 1904.

Based on the South African Law of 1909, the government decreed that a population census would be carried out, including all races in 1910, the year when the South African Union was established. Furthermore, the law stated censuses would be repeated whenever required. Thus, from 1911 to 1951, eight censuses were performed, of which four included white people, only [38].

In 1911, three racial categories were created, Bantu, mixed, and other Colored, and European/white [39]. In 1948, with the inauguration of the Nationalist Party, the segregationist history of South Africa became a political landmark. During this period, Apartheid was made official, and several laws influenced demographic statistics, of which the 1950 Population Registration Act and the Native Laws Amendment stand out 1951 Bill [37]. In 1950, three racial categories for South African citizens were officially created through the Population Registry Law, native, white, and Colored. Those people whose colors corresponded to ethnic groups were obliged to bear identity documents [39, 40]. In 1991, several amendments to this law were repealed by the Population Repeal Act, and vital records (births and deaths) were no longer collected by population groups [37].

In the 1960 and 1970 censuses, two different questionnaires were used, one intended for whites, Coloreds, and Asians, and the other for black people. Only a small sample of the black population was counted. Supposedly, the information required for the different groups was motivated by the relevance of the information attributed to each of these groups. In 1960, four racial categories fundamentally hierarchized at the capital level were incorporated into the South African census, black, Asian, Colored, and European/white [38]. In 1972, the computerized population record began, but only the data of whites, Coloreds, and Asians were recorded. Africans were registered in the computerized system in 1986 [37].

For the 1980 census, standardized data collection for all population groups was introduced; however, the question on the family structure was not posed to the black population [38]. In the 1996 census, Indians and Asians were classified into a single racial category [40]. Only in 1996 did the nationwide census adopt standardized methods for all residents of the country. In this and the 2001 census, the questionnaires were available in the eleven official languages of the country, whereas previously restricted to English and Afrikaans [38].

During Apartheid, the race was resized and represented the core of the racial segregation system imposed and the struggle against the capitalist system [27]. The Apartheid regime transformed South Africa into one of the most racialized social orders in the world [39], producing two nations, one comprising whites and the other non-whites. Thus, South Africa constituted two political communities in the same national territory [41]. Non-whites or blacks included all groups originating from Africa and Asia, or those of mixed ancestry considered to be of color (i.e., black, Colored, and Indian) and were excluded from the right to vote. White reflected all Caucasians originating from Europe and who benefitted by the Apartheid system [27]. A large part of the black population understood Apartheid to be a population policy used as a mechanism of domination to keep the number of blacks in the country and their movements under control [42].

The struggle for liberation intensified in the early 1990s by forcing negotiation with political leaders of the Apartheid settlers, culminated on 27 April 1994, with the establishment of "New South Africa" or [43]. The struggle for liberation intensified in the early 1990s by forcing negotiation with political leaders of the Apartheid settlers, which culminated on 27 April 1994, with the establishment of the "New South Africa" or "Rainbow Nation" entitled by Archbishop Tutu [43]. On the one hand, the rainbow metaphor is defended as a symbol of unity and harmony, an allusion to ethnic and racial diversity, acceptance to the social and political reality of the subnational groups. On the other hand, critics point to this metaphorical image of a single nation as non-existent, the main post-Apartheid myth, a fallacious discourse that serves to maintain inequalities linked to differences in race and class [44]. Interestingly, Brazil and South Africa were named a Rainbow Nation.

With the end of Apartheid, the discussion on the production of racially stratified vital statistics emerges. Although some defend the insertion of the racial category as an explanatory variable capable of monitoring the health conditions of disadvantaged groups, others argue that this systematic stratification goes back to the context of Apartheid [37]. In 1994, the HISs in South Africa were fragmented, independent, uncoordinated, and underdeveloped. The data collected were not adequately processed and used in the management of the services [45]. After the work developed by institutions such as Statistics South Africa, the South African Medical Research Council, and the Department of Home Affairs, the quality and quantity of demographic and vital statistical data have improved considerably. However, there is a need for significant improvements in infrastructure, software, the ability to use available technology, and improve the quality and use of information at all levels of management [46].

Historically, South Africa has a highly diversified, rigidly fragmented, and deeply divided society whose power is highly centralized [25]. A national health insurance system is projected to universalize and qualify access and protection of South Africans against exorbitant health expenditures; its success will depend on an effective information system, with coverage, quality, and standardization in the public and private sectors [47]. One of the priorities established by the National Department of Health to strengthen the health system consists of investing and improving the HIS [48].

The political history of both countries may have influenced the identification, conceptualization, and classification of race in information systems as well as determining the inclusion of this item in some systems and others not. In the Brazilian and South African contexts, no ministerial references were found that explain or justify the absence of race/skin color. In Brazil, this discussion is raised by researchers, activists, and members of the black movements. Although the inclusion of the item in all information and research systems is provided by law, implementation depends on the efforts of the current government, marking progress and setbacks in this direction. This fact denotes the importance of adopting progressive governments, which recognize the importance of the race/skin color indicator for the equitable development of the country.

In short, from the comparative analysis of the constitution and implementation of race/skin color in the HIS between both countries, it is understood that color or race classification systems are historically determined [7]. In these contexts, it is necessary to consider the consequences of not registering data according to race/skin color. However, the issue of race/skin color is an important predictor in the level of health, a social construct that explains social inequalities. From an epidemiological viewpoint, not including this aspect would inhibit evidence patterns of illness, mortality among racial/ethnic groups, and hide the disparities in access and quality of healthcare, which promulgate health inequalities. Moreover, racism would not be recognized as a determinant of health, although it is effectively systemic and has undeniable negative impacts on the health of ethnic and racial groups.

This study was limited to comparing the HIS of Brazil and South Africa regarding the constitution and implementation of race/skin color. However, it is imperative to question the governments' use of these data, given the potential that this issue has to highlight disparities, point out strategies to overcome inequities, and question the effectiveness of public policies. South African HISs are not standardized or in the public domain, making access to information difficult. Also, there is a lack of studies and ministerial documents that explain and justify how and why the inclusion or absence of the race/skin color item in HISs.

Conclusions

The HISs of Brazil and South Africa have a similar historical dimension regarding the configuration and implementation of the question on race/skin color, with inclusions and suppressions guided by political and ideological references. In both contexts, the HISs were strongly promoted in the 1990s. However, there is an absence of the color item in the HIS that is very important. Although, in these contexts, race/skin color represents a central political category, and not all HISs provide or release data by race/skin color.

Brazil has more HISs than South Africa, and the implementation of the race/skin color field is based on many demands by the black movement in the political sphere. One of the consequences of these demands is the creation of the National Policy for the Integral Health of the Black Population and ordinances legitimizing the mandatory implementation of the question in all HISs and health research. In South Africa, the implementation of the race item occurred concurrently with the creation of the respective systems, and there is no legal framework discussing the mandatory requirement in the HIS. The fragmentation of subsystems and the lack of communication between systems remain a great challenge for both countries.

In multiracial constituted nations like Brazil and South Africa, contestable rainbow nations, the race/skin color item remains emblematic and indispensable to measure the patterns of illness and death in ethnic/racial groups. Additionally, the inclusion of the item race/skin color and the respective production of quality data, categorically, demand public policies. Therefore, the governments of these two countries must recognize the importance of these health statistics and commit to the implementation and effectiveness of policies to promote equity in health.

Based on comparative analysis, this study reinforces the importance of including the item race/skin color in all information systems for monitoring health inequalities in Brazil and South Africa. Hence, it is expected to stimulate and subsidize the production of research on ethnic-racial disparities and the implementation of public policies aimed at mitigating health inequities. Indeed, the implementation of public policies focused as a mechanism of social protection to vulnerable population groups, constitute strategies of historical reparation, in the scope of health.

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Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflict of interest.

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