O MUNDO DA SAÚDE

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Cervical cancer screening in an indigenous population in the Brazilian Amazon: the case of DSEI Amapá and Norte do Pará and the *Wajãpi* Indigenous Land

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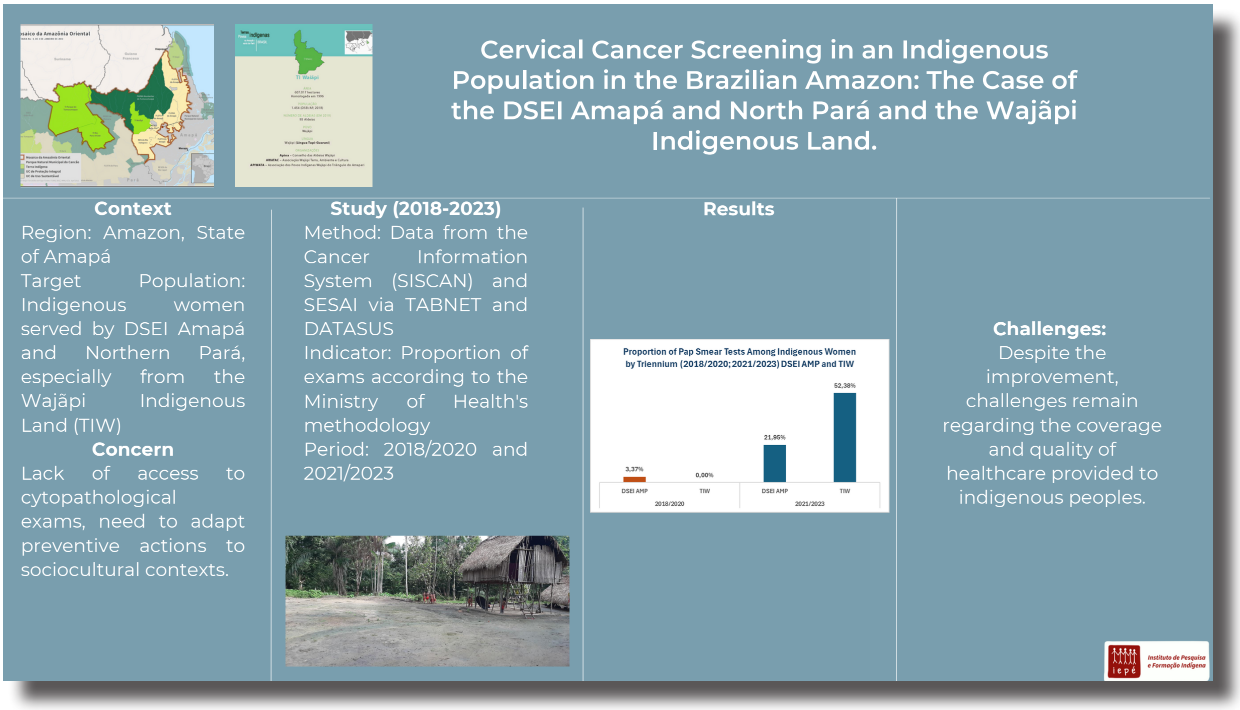
Graphical Abstract



Cervical Cancer Screening in an Indigenous Population in the Brazilian Amazon: The Case of the DSEI Amapá and North Pará and the Wajãpi Indigenous Land.

Context

Region: Amazon, State of Amapá

Target Population: Indigenous women served by DSEI Amapá and Northern Pará, especially from the Wajãpi Indigenous Land (TIW)

Concern

Lack of access to cytopathological exams, need to adapt preventive actions to sociocultural contexts.

Study (2018-2023)

Method: Data from the Cancer Information System (SISCAN) and SESAI via TABNET and DATASUS

Indicator: Proportion of exams according to the Ministry of Health's methodology

Period: 2018/2020 and 2021/2023

Results

Challenges:

Despite the improvement, challenges remain regarding the coverage and quality of healthcare provided to indigenous peoples.

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Abstract

Cervical cancer is a common and lethal neoplasm for women in Brazil, with an estimated 17 thousand new cases between 2023 and 2025. The North region has the highest incidence and mortality rates, reflecting inequalities in access to health services . Early detection and vaccination are essential for prevention, but coverage is insufficient when it comes to indigenous peoples. This is a descriptive study that seeks to analyze the proportion of cytopathological exams in indigenous women aged 25 to 64 years, considering two three-year periods, in accordance with the recommendations of the World Health Organization (WHO), based on data from the Information System of Cancer. The data were obtained from population data from the Special Indigenous Health District of Amapá and Norte do Pará. In the first three years (2018-2020), the proportion of exams was 3.37% in DSEI AMP and 0% in Pedra Branca do Amapari, a reference municipality for the *Wajãpi* people. In the second three-year period (2021-2023), these proportions increased to 21.95% and 52.38%, respectively. The significant improvement in indicators for testing among the *Wajãpi* is attributed to the Cervical Cancer Tracking Project, carried out by the Institute of Indigenous Research and Training (Iepé) in cooperation with the DSEI AMP. Although the collaboration between the *Wajãpi*, Iepé and DSEI AMP communities has produced an improvement in rates, challenges remain, especially in relation to the coverage and quality of health care provided to indigenous peoples.

Keywords: Cytopathological Examination. Indigenous Women. Intercultural Health. Access to Health. Cancer Prevention.

INTRODUCTION

Cervical cancer is one of the most common and lethal neoplasms for women in Brazil, with an estimated 17 thousand new cases for the period from 2023 to 2025[1]. The incidence of this pathology in different regions of the country is a relevant indicator of inequality in population access to health services. According to the National Cancer Institute (INCA) of the Ministry of Health, the North region, where most of the Legal Amazon is located, has the highest incidence rates of cervical cancer (20.48/100 thousand), followed by the Northeast, Midwest, South and Southeast[1]. In 2021, this pathology represented the first cause of death from cancer in women in the North region[1]. This region, due to its large territorial extension and the existence of remote and difficult-to-access areas, presents an extremely challenging scenario in tackling this issue[2]. It is also noteworthy that this region has the highest rate of indigenous populations in Brazil (44 .48%)[2].

Cervical cancer is closely associated with persistent infection with some types of Human Papillomavirus – HPV. If the primary lesions caused by HPV are not adequately evaluated and treated, the risk of developing cervical cancer is around 30%. Prevention and control measures for this type of pathology are known and effective and include early detection through cytopathological examination, adopted in public services since the 90s, and HPV vaccination[3].

In Brazil, the quadrivalent HPV vaccine was incorporated into the National Immunization Program (PNI) of the Ministry of Health (MS) in 2014, free of charge, with the gradual inclusion of target populations. Vaccination began with girls aged 11 to 13 in 2014, was expanded to the age group of nine to 11 in 2015 and expanded to girls aged 14 in 2017. In 2014, 87% of Brazilian municipalities reached the recommended target in the first dose, but only 32% reached the target in the second dose. However, there is a concentration of microregions with low vaccination coverage in the North of Brazil. Furthermore, it is important to highlight that there is still no specific and public data on vaccination coverage for indigenous peoples[4].

Therefore, analyzing data relating to the performance of Pap smears is essential for evaluating the quality of health policies implemented in relation to the prevention of cervical cancer.

Several indicators can be used, and the proportion of three-year cervical cancer screening is recommended by both the World Health Organization (WHO) and the State Councils of Municipal Health Secretaries

(CONASEMS), since 2022, to evaluate the Primary Health Care (PHC) scenario[3] (Brasil, 2022). According to the WHO, when this proportion is greater than 80% of women of screening age, considering a period of 3 years, with the guarantee of adequate diagnosis and treatment of detected cases, a 60 to 90% reduction in the incidence of cervical cancer can be achieved[3,5].

The proportion indicator offers a comprehensive and inclusive view of exam coverage, considering all women in the recommended age group who took the exam within a three-year period, especially relevant for regions with less infrastructure. Furthermore, it allows comparison with national and international results. Data collection is facilitated by information systems such as the Cancer Information System - SISCAN (cervix and breast), enabling continuous and adjustable monitoring. This indicator is essential for evaluating the effectiveness of tracking campaigns and identifying areas with the greatest needs, even though it shares limitations common to other indicators[3].

In relation specifically to indigenous peoples, in Brazil there has been, since 2002, the National Policy for Health Care for Indigenous Peoples (PNASPI), which established the Indigenous Health Care Subsystem (SASI-SUS). The subsystem operates through the Special Indigenous Health Districts (DSEIs) to guarantee differentiated primary care actions for people living in Indigenous Lands. As of 2010, the DSEIs are coordinated by the Secretariat of Indigenous Health (SESAI), directly linked to the MS[6,7].

Despite the existence of PNASPI, SESAI and the DSEIs structure, several health indicators of indigenous populations are still worrying[4]. In a cohort study carried out on health inequities related to race and ethnicity in cervical cancer in Brazil, between 2004 and 2015, analyzing the Brazilian mortality database, an 80% higher risk of mortality from cervical cancer was calculated in indigenous women, when compared to white women[8].

One of the difficulties relating to the study of disparities between the indigenous and non-indigenous population is the lack of access to reliable data that accurately estimates these differences at national and local levels.

Thus, the present study focuses on the analysis of data on the proportion of pap smear tests carried out at the DSEI Amapá and Norte do Pará, which serves a diversity of indigenous peoples, including the *Wajãpi, Palikur, Galibi-Marworno, Karipuna, Wayana* and *Tiriyó* peoples. The study also emphasizes data from the *Wajãpi* population, who inhabit the *Wajãpi* Indigenous Land (TIW), in the municipality of Pedra Branca do Amapari, in Amapá[9].

It is noteworthy a quick characterization of the *Wajãpi*. These people speak a language from the Tupi linguistic trunk, inhabit the *Wajãpi* Indigenous Land (TIW) located in the municipalities of Pedra Branca do Amapari and Laranjal do Jari in the State of Amapá. The TIW has 607,000 thousand hectares and was demarcated and approved in 1996. The *Wajãpi* population, according to the Indigenous Health Care Information System (SIASI) of 2022, is 1,933 people. The population is distributed across 129 villages, according to data collected by the Council of *Wajãpi* Villages (Apina) and the Institute for Indigenous Research and Training (Iepé) in 2023, which are occupied seasonally[9]. The *Wajãpi* have a history of near extermination in the 60s and 70s, due to measles epidemics transmitted especially by hunters and miners, before the demarcation of the Indigenous Land[10]. After a demographic recovery and, in more recent times, the *Wajãpi* revived their fear again in the face of the Covid-19 pandemic, but they went through the most critical period with few deaths. Between 2020 and 2021, another fear gripped the *Wajãpi*: two young women died as a result of gynecological diseases, one of them with a confirmed diagnosis of cervical cancer. Furthermore, many women were presenting gynecological complaints, even after care by the health team at TIW and specialists in Macapá. *Wajãpi* complaints of lack of assistance, in fact, are corroborated by public data available from the Cancer Information System.

In order to better understand the situation, a study of the indicator of the proportion of cervical cancer exams is proposed here con-

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sidering two three-year periods, 2018-2020 and 2021-2023, according to the latest data available in SISCAN (cervix and breast). Although the period of this study covers a critical moment in health, due to the Covid-19 pandemic, 2/3 of the first three-year period (2018-2019) preceded the pandemic and 2/3 of the second three-year period (2022-2023) situation had already stabilized. As SISCAN data is collected annually, the pandemic does not appear to have produced a significant difference in the data analyzed[10].

Furthermore, in the data analysis, a local health action strategy will be presented organized by the Council of *Wajãpi* Villages - Apina, in partnership with the Institute of Indigenous Education and Research (Iepé), which produced a significant impact on local indicators.

The data used were anonymized and are in the public domain, and submission and approval of the research by a Research Ethics Committee is not necessary, in accordance with resolution No. 510 of the National Health Council, dated April 7, 2011[1].

METHODOLOGY

This is a descriptive study that seeks to analyze the proportion of cervical cytopathological exams in the eligible age group, comparing two three-year periods - before and after the COVID 19 pandemic - and that describes one of the possible strategies for improving access to the primary screening exam. Data on cytopathological examination of the cervix come from the Cancer Information System - SISCAN (cervix and breast), available through the TABNET platform, provided by the Department of Informatics of the Unified Health System (DATASUS)[10].

Regarding population data, it is necessary to consider that there is an inaccuracy, since the last indigenous census released was from 2010 and the information from the 2022 census has not yet been published and is preliminary[12].

SESAI uses its own system to monitor the indigenous health situation, the Indigenous Health Information System (SIASI), but complete demographic data with details are not publicly disclosed. However, this information can be accessed through public accountability instruments, such as the annual management reports and Work Plans of entities affiliated with SESAI[9].

In this way, data from the management report of the DSEI Amapá and Norte do Pará will be used, extracted from the Work Plan for actions of the Ovídio Machado Foundation, which establishes the goals for hiring human resources for the DSEI and uses updated data from the SIASI of 2022[9]. According to the document, the total population of the DSEI is 14,380, and there are 2,519 women aged 25 to 64, the recommended age for screening for cervical cancer[9].

Still according to data from the report, the indigenous population residing in the *Wajãpi* Indigenous Land is 1,933 people, corresponding to 13.3% of the DSEI population.

The available data do not specify the population distribution by sex and age group of the different Indigenous Lands served by the DSEI, therefore, in order to be able to calculate *Wajãpi* women aged 25 to 64, an estimate was prepared. Despite the specificity of each population, the age and sex pyramid between the general indigenous population of the DSEI and the TIW population does not present specific factors that could produce significant differences regarding the calculation of the local denominator. Thus, to estimate the population of *Wajãpi* women aged between 25 and 64, the proportion of the *Wajãpi* population in relation to the DSEI (13.3%) was used, applied to the total number of women aged between 25 and 64 years (2519), obtaining the result of 336[9].

To calculate the proportion of exams carried out, the ratio of women aged 25 to 64 who took the exam in the last 3 years was used, for the three years 2018-2020 and 2021-2023, over the total population of women aged 25 to 64, at DSEI and TIW, in accordance with the recommendation of the MS, CONASEMS and WHO[3,9].

Number of women aged 25 to 64 who underwent cytopathological examination in the last 3 years
Number of women aged between 25 and 64 registered

RESULTS

In order to capture specific data from cervical cytopathological exams in indigenous women from all municipalities in Amapá and specifically from *Wajãpi* women, we used data from the reference municipality of the *Wajãpi* population, which is Pedra Branca do Amapari. In the table below it is possible to compare the total number of exams carried out on indigenous women in the state of Amapá and *Wajãpi* women in the two selected three-year periods, based on data from the municipality of Pedra Branca do Amapari.

Table 1 - Number of cytopathological exams in indigenous population by municipality of residence in the state of Amapá.

Municipality of residence	2018	2019	2020	Total	2021	2022	2023	Total
Serra do Navio	0	0	0	0	0	0	0	0
Amapa	0	0	0	0	0	0	0	0
Pedra Branca do Amapari	0	0	0	0	1	134	41	176
Calcoene	0	0	0	0	0	0	0	0
Cutias	0	0	0	0	0	0	0	0
Ferreira Gomes	0	0	0	0	0	0	0	0
Itaubal	0	0	0	0	0	0	0	0
Laranjal do Jari	0	0	0	0	0	0	1	1
Macapa	8	55	22	85	43	111	158	312
Mazagao	0	0	0	0	0	0	0	0
Oiapoque	0	0	0	0	0	41	23	64
Porto Grande	0	0	0	0	0	0	0	0
Pracuuba	0	0	0	0	0	0	0	0
Santana	0	0	0	0	0	0	0	0
Tartarugalzinho	0	0	0	0	0	0	0	0
Vitoria Do Jari	0	0	0	0	0	0	0	0
Total	8	55	22	85	44	286	223	553

As the results show, in the first triennium analyzed, only 85 exams were carried out on indigenous women in the state of Amapá (8 in 2018, 55 in 2019 and 22 in 2020). In the second three-year period, 553 exams were carried out (44 in 2021; 286 in 2022 and 223 in 2023). Considering the analyzes of the indigenous population of Pedra Branca do Amapari, no exams were carried out in the first triennium and in the second a total of 176 exams were carried out, (1 in 2921; 134 in 2022 and 41 in 2023).

The same data is corroborated by the table below, which presents the proportion of cytopathological tests carried out on indigenous women in Amapá and Northern Pará and the proportion of tests carried out on *Wajãpi* women.

Table 2 - Proportion of cytopathological tests performed on the population of indigenous women in Amapá and TIW, in the three-year periods 2018-2020 and 2021-2023.

Place	Period	No. of Exams	Population of women aged 25-64	Ratio
DSEI AMP	2018-2020	85	2519	3,37%
TIW	2018-2020	0	336	0,00%
DSEI AMP	2021-2023	553	2519	21,95%
TIW	2021-2023	176	336	52,38%

- DSEI AMP: DSEI Amapá
- TIW: *Wajãpi* indigenous land

The data presented in table 2 point to a minimum percentage of cytopathological exams being carried out at both the DSEI (3.37%), for the first three-year period, 2018-2020. In the case of indigenous women residing in the municipality of Pedra Branca do Amapari, no examination was carried out.

In the second three-year period, the percentage increase obtained shows a significant improvement. Despite this increase, the general DSEI data (21.95% proportion) point to a scenario very far from the WHO target and the health indicators agreed for Primary Care in Brazil, of 80% coverage of the population of women of 25-64 years old[3,9]. The situation in TIW (52.38%), even though it does not reach the target indicators, shows a pattern of improvement and greater coverage than the situation presented for the general population of indigenous women in Amapá.

From 2020 onwards, it would be understandable, as a result of the pandemic and the prioritization of actions aimed at combating COVID-19, that the DSEI's health programs would be compromised, resulting in a drop in the number of pap smear collections, rapid testing and others. However, what is observed is exactly the opposite: while in the first three years, where 2/3 of the period there was no pandemic, the data is extremely low. In the second three years, in the middle of the pandemic, collection data showed a significant increase.

As there was no specific restructuring of the work of the DSEI team to carry out cytopathological exams in the second three years, it is concluded that the increase in the number of exams was caused especially by the health action carried out from December 2021 to December 2023 by Iepé - Institute of Indigenous Research and Training in partnership with DSEI Amapá and Norte of Pará.

DISCUSSION

The present study explains the difficulties faced by indigenous peoples in guaranteeing access to quality health care services, despite the existence of the PNASPI. The data shows that there is still a considerable distance from the rates recommended by CONASEMS, MS and WHO[9]. These low rates of an indicator widely used in Primary Care help explain what several studies point out: the greater vulnerability of indigenous women to die from preventable causes. In this scenario, the study carried out by Goes and collaborators stands out, with data from the Cohort of 100 Million Brazilians, linked to the Brazilian Mortality Database, from 2004 to 2015 (n = 20,665,005 adult women) and which points to a 80% higher cervical cancer mortality in Indigenous women (adjusted mortality rate = 1.80, 95% CI 1.39-2.33) compared to white women[8].

The state of Amapá, in the North Region and where TIW is located, in 2017 presented double the mortality rates from CC when compared to national rates during the same period. In Brazil, in 2017, CC was the main cause of premature mortality among young women (25–29 years old) in 2017 (years of life lost - YLL: 100.69/100,000 women)[1].

It is necessary to pay attention to the complexity of this situation, when taking into account specific sexuality patterns of indigenous peoples which, in general, point to the beginning of sexual life earlier than non-indigenous women and to early exposure and infection to the HPV virus, as well as other sexually transmitted infections (STIs)[13,14]. Sociocultural characteristics of sexual behavior, the low supply of screening exams and barriers to accessing health services point to an association of risk factors for the development of cervical cancer.

Despite the far from ideal scenario, it is possible to see, from the data explained, that there was a significant change in the proportion of exams carried out at the DSEI (3.37% 2018-2020; 21.95% 2021-2023) and mainly in the indigenous population of the municipality of Pedra Branca do Amapari (0% 2-18-2020; 52.38% 2021-2023).

One of the explanations for this change in scenario can be found in the Cervical Cancer Screening Project, organized based on a request made by the Council of *Wajãpi*-Apina Villages to Iepé - a Non-Governmental Organization that has been operating in TIW for over 20 years - , so that activities could be carried out that enhanced women's health actions, with a specific focus on cervical cancer screening.

Even though Iepé does not work specifically with health care, in response to the communities' appeal, it was developed, together with partners, a specific intervention project for *Wajãpi* women, focusing on qualified listening to gynecological problems. One of the fundamental partners for carrying out this project is the Xingu/UNIFESP Project, responsible for organizing and implementing tracking actions in indigenous territory Xingu Indigenous Park. The Xingu Program developed, along with DSEI Xingu, over the years, a line of care for cervical cancer screening in indigenous women considering cultural and territorial specificities, in addition to creating strategies to deal with weaknesses in the reference health care for the territory[14].

From the organization of local data, considering the different regions, number of villages, forms of access, percentage of women to be served and cultural specificities, a project was designed to carry out the collection of cytopathological examinations of the cervix and care for gynecological complaints of *wajãpi* women.

Concomitantly with this preparation, there was a negotiation with the DSEI AP and Norte do Pará, so that the action could be carried out in an integrated manner with the work of the Multidisciplinary Indigenous Health Team, which works to provide health care within the TIW. Arrangements were also made regarding the forwarding of collected material to the DSEI reference laboratory and the monitoring of women with altered results for treatment at Hospital do Amor (HA) in Macapá, which is a specialized center for the treatment of gynecological problems. It was also essential to agree on data sharing and mutual reinforcement to ensure that women with altered exams could carry out follow-up consultations.

The action was organized in order to respect

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the social organization of the *Wajãpi* who are distributed in small villages in different regions of the TIW. Instead of the team staying at a station for care, which is how preventative collection generally occurs, mobile services were carried out in 5 regions. From November 2021 to December 2023, the action team visited around 70 villages in TIW, carrying out preventive examinations for the early detection of precursor or pre-cancerous lesions.

The issue of time was another significant factor. In each region, meetings were held with women, respecting family groups, in order to provide sensitive listening related to gynecological problems, fears and doubts. In addition to conversations about STIs, the topic of cervical cancer was central to understanding the importance of cytopathological examination. A moment was also dedicated to a thorough explanation of how all the exams offered would be carried out. Afterwards, preventive exam collection and rapid tests for syphilis, HIV and Hepatitis B and C were offered. During the collection, a syndromic approach was carried out, providing on-site treatments for some gynecological problems.

Guaranteeing the return of exams, with appropriate explanations, was essential for women's adherence and continuity of screening actions. A frequent complaint from *Wajãpi* women regarding previous collections was not receiving the results.

It is worth paying specific attention to the issue of language, as it carries specific knowledge, logic and concepts related to the body, sexuality, diseases, etc. In many indigenous peoples, older women have great difficulty with Portuguese. Even with the participation of younger interpreters, there are many difficulties in communication and understanding[15].

Another point of discussion for carrying out the exam was the offer to pregnant women, which did not occur in some cases, due to the local health team's fear of any complications during pregnancy. In the action carried out at TIW, some pregnant women expressed their desire to take the exam. This is an important point, as fertility rates in indigenous women are high, it is common for women to have a short interval between pregnancies. Failure to offer the exam due to pregnancy may make it impossible for women to perform it as regularly as necessary, putting them at risk[9].

In addition to the points mentioned above, the Tracking Project ensured, during the period of its implementation, adequate monitoring of indigenous patients who needed follow-up, with attention to advance notices about the day of the consultation, guaranteeing travel and avoiding interruption of care and treatments.

Finally, it should be highlighted that the joint construction with the target communities or indigenous organizations of the people involved in the comprehensive planning of the action was fundamental for the adhesion of *Wajãpi* women to the project and the improvement of local indicators.

Finally, it is worth highlighting a weak point in this study, which is also faced by many other researchers in the area of indigenous health: the difficulty in obtaining population data (used by health) and specific health indicators. The publication of SIASI data was, in fact, one of the recommendations determined by the Federal Supreme Court in the Claim of Non-compliance with Fundamental Precept 709, filed by the Articulation of Indigenous Peoples of Brazil (APIB) in 2020 against the Brazilian government[16]. Without data, monitoring is not possible. The absence of a demographic database can also lead to inappropriate calculations, even though all possible care was taken to mitigate possible biases in this regard in the present study.

CONCLUSION

This article presents an overview of a locally calculated indicator, fundamental for evaluating the quality of health care, which is the proportion of Pap smears performed. From the data analyzed, disparities in access to health faced by indigenous peoples are evident, for the indigenous peoples of the region chosen for the study.

Despite this, the article presents possibilities for proposals that can mitigate this issue, taking into account culturally appropriate actions, which involve planning together with the local community and all actors working in this field.

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All authors have read and agreed to the published version of the manuscript.

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