

Public Involvement & Engagement in health inequalities research on COVID-19 pandemic: a case study of CIDACS/FIOCRUZ BAHIA

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Abstract

Introduction

Health inequalities in Brazil have deepened on Covid-19 pandemic, and the most vulnerable people were the more affected. A multidisciplinary team from Cidacs/Fiocruz Bahia developed a Social Disparities Index for Covid-19 (IDS-COVID-19) to support the evaluation of effects of health inequalities on the pandemic in Brazil. Public Involvement and Engagement were the pillars of this research because they allowed us to access first hand experiences about the social context in our country.

Objectives

This paper aims to describe our Public Involvement and Engagement experience by analysing our challenges, strategies, activities, results, and lessons learned during the construction of IDS-COVID-19.

Methods

The basis of the IDS-Covid-19 public engagement model was the participation of different social groups through methods and techniques that allow dialogue. Several activities and communication products supported the continuous interactions. Another guideline was the inclusion and the welcoming of participants from the beginning of the project to ensure that the participant's contributions could drive decision-making about the research.

Results

Participants made several contributions to the research as a new layer of information to the Index, and improvements were made to the interactive panel. They also compromised to support the dissemination and use of the product. Eight representatives of community groups and 29 policymakers participated in our engagement activities during the project. More than 500 people were in our open webinars. In addition, more than 140 news items about IDS-Covid-19 were published in national and international media.

Conclusions

We highlight as lessons learned the adaptation of some dissemination formats to the public, and the necessity of being flexible and accessible to participants. We strengthened the relationship with relevant stakeholders by exploring individual conversations by phone, WhatsApp, email, and interviews to produce a documentary that registered this whole experience. Cidacs/Fiocruz Bahia has also embedded public engagement and involvement in the study agenda.

Keywords

Public engagement; public involvement; social inequalities; community groups; policymakers; pandemic; Brazil

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Background

Pandemic of Covid-19: Brazilian context

A World Bank study published in 2019 showed that in Brazil, 51.7 million people were living below the poverty line, that is, on less than US\$1.90 a day, and 24.7% of the total population had a monthly income of less than US\$100 [1]. In March of that year, income inequality measured by the Gini index, on a varying scale from 0 to 1, reached 0.6257 – the highest level ever recorded by the Brazilian Institute of Economics of the Getúlio Vargas Foundation (FGV/IBRE) [2]. The Covid-19 pandemic, announced on March 11 2020, by the World Health Organization (WHO), intensified a situation of social inequalities in Brazil, which recorded more than 685,000 deaths by November 2022.

The heterogeneity of the sociodemographic characteristics of the Brazilian population meant that different segments of society faced this period in different ways. Vulnerable social groups which do not have guaranteed social rights, such as women, black people, and poor people who live in slums and residences with high housing density without basic sanitation, among others, were greatly affected. Many of these social segments suffered from the substantial loss of income and employment, increase in gender and age violence, and the growth of hunger in the country, in addition to difficulties in accessing health services and complying with measures to prevent contamination of the virus.

According to the Brazilian sociologist Nísia Trindade Lima, president of the Oswaldo Cruz Foundation (Fiocruz) – the biggest Brazilian public health research institution: “The pandemic is not the same for all countries, nor is it the same for everyone within the same country or city. Many say we are all in the same boat. However, this is not quite the case. We are all experiencing the same storm in the same sea. However, it is as if some were traveling on transatlantic ships, others on yachts, and others on sailing boats or even canoes” [3].

To measure the effects of social inequalities in health during the Covid-19 pandemic in Brazil, researchers from the Center for Integration of Data and Knowledge for Health (Cidacs/Fiocruz Bahia), led by epidemiologist Dr. Maria Yuri Travassos Ichihara, developed the Social Inequalities Index for Covid-19 (IDS-COVID-19). The research project “Evaluating the effects of social inequalities in a low and media-income country” was one of 10 among over 400 proposals from 69 countries contemplated by the Grand Challenges ICODA Pilot Initiative, promoted by Health Data Research UK, and funded by the Bill & Melinda Gates Foundation and Minderoo Foundation. The work was conducted over 12 months involving epidemiologists, mathematicians, statistics, data scientists, communicators, an anthropologist, and had public engagement in science as one of its pillars.

This article addresses the public engagement in science carried out at Cidacs during the construction of the IDS-COVID-19, highlighting the challenges faced, the strategies and activities implemented, the contributions made to the project, and the lessons learned. This effort has the potential to contribute to strengthening the inclusion of public engagement as a requirement of the research projects, as it can increase the quality of research and confidence in science in the context of legitimacy crisis experienced by academic community. Since

the beginning of the investigation, public managers in the health area, leaders of social groups, communities, and non-governmental organisations have been helping the researchers by sharing relevant experiences for the Index construction and the scientific dissemination products, such as the documentary.

Our approach

Faced with the disruptive consequences of the socio-sanitary crisis caused by the Covid-19 pandemic, it became necessary to bring IDS-COVID-19 researchers closer to more vulnerable groups and policymakers. More than disseminating the research results to different audiences, it was essential to hearing segments of society from the beginning of the project until its completion, with public engagement in science as a guiding concept.

Recognised for understanding social participation as a fundamental part of building scientific knowledge, the public engagement movement in science seeks to bring scientists closer together with the most diverse social groups. The central idea is the construction of research projects and public policies together with members of social groups exchanging different points of view and knowledge [4].

Public engagement in science means the inclusion of voices commonly excluded from public debates, which are not involved in scientific disciplines as a professional activity [5]. Thus, public engagement work should focus on dialogue, involving different audiences and the construction of a workflow between scientists and participants. By sharing their experiences, these citizens can play a fundamental role, helping to improve the quality of research or support decision-making about public policy. “There are different types of knowledge [...] it is therefore essential to listen to distinct groups of interest and the experiences they can bring to the discussion. Not just experts have knowledge. Other forms of knowledge are also relevant” [6].

The UK and the USA are responsible for bringing this complex idea to the scientific scenario, shaping its theory, methodology and practice. These countries and their authors firstly build this field considering the contexts and needs of their realities. This concept has since been adopted more widely. As such, scientists from across the world have been adapting the Global North perspective of “Public Engagement with Science” to their own scientific realities.

In Brazil, there are examples of social participation in research led by medical doctors, professors, and policymakers since the 1970s/1980s. This has led to a new focus on including people and democracy in the delivery of policy and practice, named “Collective Health”. This movement was central during the Brazilian re-democratization, after the dictatorship (1964–1985), with the Brazilian Universal Healthy System (SUS), a national health system created after the 1988 Federal Constitution. Social participation is one of the guidelines of SUS and it has been an important arena of discussion and action to control epidemics like Dengue and Zika and to treat conditions such as Syphilis and Leprosy, bringing together lay people, policy makers, medical workers, and researchers [7, 8]. These examples inspire some Brazilian scientists to include social participation in research, but, frequently, not with the label of public engagement.

Although there is not a strong history of public engagement in science in Brazil, this work aimed to face this concept and its articulation within the context of a country in the Global South. In this way we developed a work plan that would allow the participation of different social segments in the construction of IDS-COVID-19. The interactions between scientists and non-scientists proved imperative to produce an instrument that could be appropriated by the Brazilian population, with the potential to generate social impacts by supporting the production of public policies.

Why implement public involvement and engagement in SDI-Covid-19?

An issue raised by epidemiologist Joilda Nery, from the Universidade Federal da Bahia (UFBA), during the project launch event, on December 6, 2021, helps to explain the importance of public engagement in science at Cidacs. This was articulated as: "Are we really producing something that benefits the people who are being affected, or who are going hungry because of social inequalities?" PhD Candidate in anthropology and *quilombola* Marta Quintiliano, from the Universidade Federal de Goiás, endorsed the statement: "It is always this way: they ask, they say things, and then we don't know where it went, we don't know about this return. I wonder when these people are going to be heard?"

A recent investigation about the perceptions of different social actors regarding personal data used for scientific research found a gap in monitoring and returning research results after collecting information [9]. According to the authors, this process generates a lack of trust and has stimulated some groups, such as traditional communities, to take alternative measures to ensure their rights, for example, the production of specific terms for agreement between the group and the scientists.

The implementation of public science engagement in IDS-COVID-19 was motivated by the search to create an actual and positive impact for public managers, representatives of communities, and society in general. Different social segments' participation allowed the project to capture new perspectives, validations, and decision-making. In addition, it supported efforts to make the Index a measure that could be useful to the stakeholders involved.

Building the relationship between participants and researchers was also relevant to expose the scientific production processes among non-scientists. This movement has the potential to contribute to increasing confidence in science in the context of the legitimacy crisis experienced by the academic community.

Challenges and strategies to promote public engagement in this research

Some challenges were faced to develop this public engagement initiative. A lot of restrictions imposed by the pandemic, which required social distancing to fight the spread of SARS-CoV-2, made face-to-face meetings impossible. Besides that, for some of the researchers this was the first experience of social participation in science and as the project lasted only one year, they expressed their insecurities about public engagement

actions. On the one hand, there was hesitation to participate in some activities since part of the team had never worked with engagement in previous projects. On the other hand, there were uncertainties and worries in raising expectations of the groups that could not be met - such as undertaking discussions about collected data. Therefore, our main problem was how to incorporate a public engagement initiative in a research project about health inequalities and health data during the Covid-19 pandemic.

The starting point for this research was to define the basis for how to conduct the public engagement work. Values such as transparency, diversity, ethics, and equitable practices were at the heart of decision-making on IDS-COVID-19 because they were articulated with the project's central theme, which was related to social inequalities in health. In this way, it was necessary to develop mechanisms to allow participants to accompany the Index production process - including problems and limitations faced - to ensure that every opinion was heard, noted, and discussed collectively. Also, that the people invited had different types of experiences and characteristics to represent the full breadth of diversity within the Brazilian population.

It was necessary to identify with the group of researchers which perspectives of engagement and involvement would be chosen by them, considering the medium and long-term objectives of the project. All this required an effort from the team to recognise this place and only then think about the public and more appropriate strategies.

Internal webinars conducted by members of the team dedicated to developing public engagement - two communicators and an anthropologist - were important to discuss the theme and support the public engagement plan. The researchers were also committed to participating in activities, creating dialogues with different audiences, and using accessible language for non-academics. The group decided to implement a collaborative form of public engagement, exploring open dialogues with stakeholders to share valuable experiences from different points-of-view. It is well known that black and poor people have a large history of exclusion in our country as well as women in their professional and personal lives and they suffered much more during the pandemic. Therefore, the criteria to choose stakeholders to participate in this research were representative of community groups of different social, gender and racial ethnic backgrounds from different regions, and representatives of policymakers from states, and municipalities. Their availability to participate in online activities was also considered.

We invited policymakers, researchers interested in the theme, representatives of community groups and journalists to participate in our research project considering the national cultural, economic, and ethnic diversities. A focus was on ensuring representatives of community groups that work with black populations, slums, black women, food insecurity and human rights were included (Figures 1, 2).

The strategies implemented to build an environment of trust between researchers and participants included preparing the team of researchers through internal meetings, carrying out products and communication actions, and building relationships with stakeholders through interactions, both individual and collective, in addition to the scientific dissemination of results. The actions were planned according

Figure 1: Community groups representatives who were part of the project

Black Women's Group Mãe Andresa	An entity that makes up the Northeast Black Women Network and focuses on the state of Maranhão
Center for Art and the Environment	The Center, founded in 1995, focuses on Socio-environmental Development in predominantly black communities in the Itapagipe Peninsula region, an area of Salvador that encompasses 14 neighborhoods in Cidade Baixa.
Human Rights, Crisis and Covid-19 Observatory	The initiative started in 2020, bringing together dozens of social organisations and popular movements to systematise information about human rights and the pandemic.
Black Women's Network for Food and Nutritional Sovereignty and Security	The entity works to articulate with civil society organisations to propose sovereignty's public policies for food and nutritional security for the black population, especially black women.
Black Women's Institute of Amapá	The entity carries out several projects with black populations in the State of Amapá and riverside regions and borders with Pará and French Guiana.
Black Women's Network of Pernambuco	It is part of the Northeast Black Women's Network. Its focus is on Pernambuco. The Network supported people in building projects in smaller organizations to support collectives and actions on the street to encourage vaccination.
Favelas Unifying Panel	This is a collaborative initiative to consolidate covid-19 data on probable and confirmed cases, and deaths based on reports from collectives, favela reporters of Rio de Janeiro, panels published by the government, and press clippings.

to the background of each group, listening to their contributions, and ensuring these groups felt engaged with the progress of the project. In this sense, the participation and the dialogue were the base of the methodology used to face the challenges and subsidise the planned solutions. Interactions occurred continuously through multiple activities and communication products. These strategies were designed based on literature and document reviews about previous public engagement initiatives in other countries [4, 10, 11].

The first interactions were very difficult because several public managers and civil society organisations had implemented home working policies. It was also necessary to consider the difficulty of securing adequate time in the busy schedule of the potential participants, due to the health emergency. After identifying their contacts, we had individual conversations to invite them to participate in the

project. At this point, we presented Cidacs, IDS-Covid-19, and the engagement activities that were being planned, and we collected information about their organisations and their first impressions about the project.

In the opening event, we presented the project and strengthened the relationship with our stakeholders. Besides that, we invited representatives of policymakers and community groups to discuss with researchers about the health inequalities during the pandemic. We connected with 129 attendees via Zoom and Youtube.

As the development of the IDS-Covid-19 took place, these partners were informed about the steps through videos, news published on the project website, technical meetings, and discussion groups (Figure 3). In the case of public policymakers, two online technical meetings were scheduled and held. The first one was held in October 2021 and brought

Figure 2: Location of the stakeholders invited to participate in building the Index

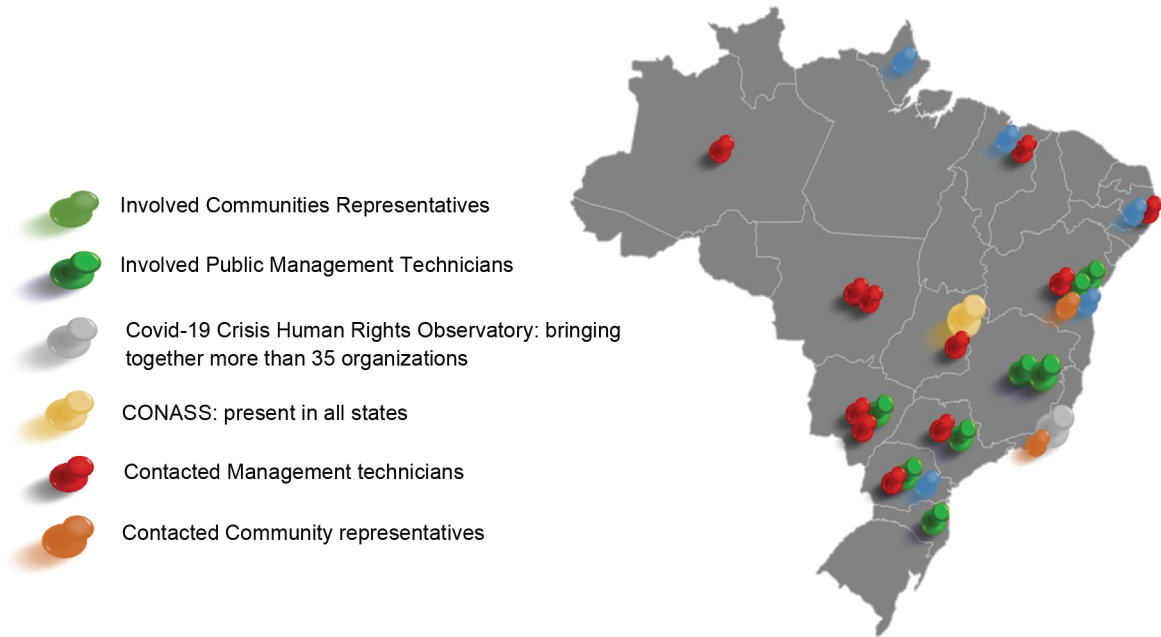
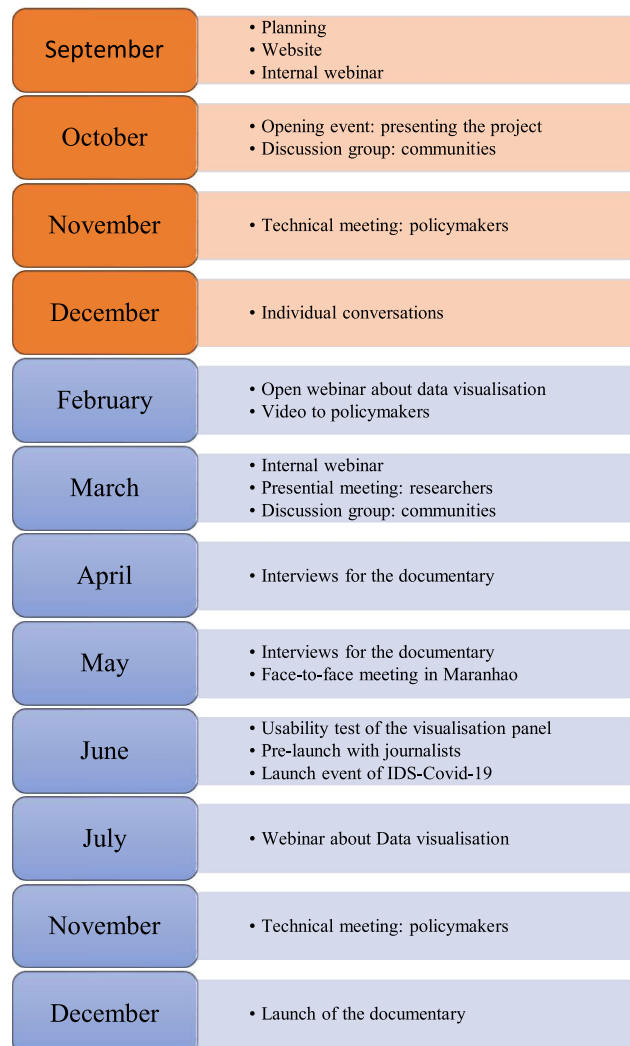


Figure 3: Timeline of public engagement activities during IDS-Covid-19



together 29 health managers, members of health councils from different Brazilian states – Bahia, São Paulo, Mato Grosso do Sul, Amazonas, Santa Catarina, Paraná – who worked at the municipal or state level, in addition to members of the National Council of Health Secretaries (Conass), which represents the 27 states health secretaries of Brazil. The researchers showed how they were building IDS-Covid-19 and collected some ideas from them about how to improve the information provided by the Index.

A year later, in November 2022, with the IDS-Covid-19 ready, the group discussed new possibilities for its use in public management. Around 70 people attended this second online technical meeting, showing the improvements in the Index and the insertion of new perspectives, such as the comparison of IDS-COVID-19 with vaccination coverage indicators. The following states and cities opened dialogue channels through the project's process: Bahia, Pernambuco, São Paulo, Minas Gerais, Amazonas, Goiás, and Rio Grande do Sul; Salvador, São Paulo, Curitiba, Belém, Belo Horizonte, Campo Grande.

With community groups representatives, the online meetings took place in the format of discussion groups. The first one, in November 2021, debating was based on questions relating to the main difficulties in accessing information about the pandemic and Covid-19, the problems caused by misinformation, the alternatives found, and what information is most important for each group within the broader public when it came to health issues. The second meeting, held in March 2022, was intended to help understand the actions developed by these groups during the pandemic, in addition to presenting the progress of the Index construction. Meanwhile, individual conversations and messages sent by e-mail and WhatsApp were important to update participants about the project and collect more ideas as an audiovisual product that became the documentary.

The aims of the documentary “Beyond the distancing: dialogues to understand the social inequalities on Covid-19 pandemic” was to present the multiples experiences of the public engagement in IDS-COVID-19. It was built through the testimonies of researchers and participants, as well as some archive images of the work in Cidacs and of the webinars and meetings. The documentary was more than an audiovisual piece to disseminate this research project to different publics in an attractive narrative, as it was also an opportunity to maintain this dialogue. During the interviews, it was possible to collect more information about the pandemic in the different contexts of participants – community groups or policymakers mainly – and share the work-in-progress with them. We conducted 32 interviews, 18 of which were via Zoom.

We also visited the Black Women's Group Mãe Andresa in Maranhao to disseminate information about Cidacs and IDS-Covid-19, to record testimonies about the social inequalities in pandemic with members of the group for the documentary and to collect ideas and identify challenges to continue the public engagement at Cidacs.

Part of the project's activities included thematic webinars on social inequalities in health and visualisation of health data. On these occasions, representatives of policy makers and of community groups that followed the project were invited as speakers or listeners. Some of them were also heavily involved in usability testing of the data visualisation dashboard of

the IDS-COVID-19¹. In addition, the group organised a pre-launch of the index in a meeting held with journalists and strategic institutions that could disseminate both the tool and the results shown. The launch event of IDS-Covid-19 had presentations of the team, speeches of representatives of policymakers and community groups.

The research team also worked on producing a website, a policy brief for managers that detailed the main aspects of the Index, an informative folder on the Index, posts on Cidacs social media, and an institutional video.

Results and impacts

The public engagement carried out during the construction of the IDS-Covid-19 resulted in advances for research, researchers, and Cidacs. Suggestions from invited participants led to decision-making in the project. Policymakers indicated the need to include a level of information on the Index that was more suited to the work routine in health management in Brazil. As a result, the index included an estimation of difficulty to health access according to the existing health services within the macroregions health according to regionalization rules of the Unified Health System in Brazil (SUS). Also, we added another option for visualisation of the IDS-Covid-19 at the level of the health regions – areas formed by border municipalities with similar cultural, economic, and social characteristics grouped for better planning and execution of health services [12]. They also promised to support the dissemination and use of the Index through their colleagues across the whole country.

Community representatives also suggested more efficient narrative and thematic formats for scientific dissemination, as well as explaining how the knowledge produced in the project could be explored by organised civil society groups. As a result of this dialogue, the documentary “Beyond distancing: dialogues to understand social inequalities in the covid-19 pandemic” [13] was produced, which, at over 55 minutes, reflects on the pandemic, social inequalities in Brazil, and challenges and solutions that enabled the implementation of public science engagement during the construction of the IDS-Covid-19.

Social participation in the project also influenced the researchers to add a filter to the interactive panel that highlights information from the index in cities that have favelas, which were areas with a high incidence of Covid-19 cases in Brazil. This digital tool also got improvements based on a usability test carried out with the participation of policymakers, community representatives, journalists and invited researchers, to ensure better accessibility of the information brought by the Index to the various segments of the public.

Another important set of results related to the development of a model of public engagement in science suitable for Cidacs, a data research centre that explores large volumes of administrative data on the social and environmental determinants of health and evaluates social policies. From the dialogue with policymakers, representatives of communities and journalists, new ideas emerged to improve the formats of meetings between the public and researchers, such as the conversation round and discussion

¹<https://ids.cidacs.org/>

group, and new interests in research topics carried out by the institution, such as tuberculosis, child mortality and vaccination.

Among the IDS-Covid-19 researchers, it was also possible to collect valuable information for evaluating the engagement process. During the 34 interviews for the documentary and for the scientific dissemination materials, we included questions such as "What do you understand by public engagement in science and why is it important?" and "How do you evaluate the public engagement of science developed in the project?" for researchers and research participants.

Responses highlighted the contribution of social participation in building knowledge more linked to the real world, for example: "I think [public engagement in science] extremely important because science itself is made to impact society and to bring about change," (AA, statistics researcher).

"The great differential of this project, perhaps, was because we tried to add several people, from different sectors, with different opinions and experiences to contribute to the project" (MB, computer science researcher).

Another researcher reflected on the historical separation between science and society that subverted in this project, as follows: "Research is seen as elitist and the social movement is seen in a smaller way. This causes fissures, causes noise. What we have been doing to carry out the engagement is to find gaps in this context to bridge these cracks to make this engagement real, concrete, and true" (EG, epidemiology researcher).

In addition, during the interviews for the documentary with community representatives and policymakers, it was possible to capture important information for evaluating the engagement process carried out throughout the research project, for example: "I was surprised that, since the beginning, the product was very organized. In terms of bringing information and bringing actors to the centre of the dialogue. In our meetings, this was very nice. There was always the main group approach, explaining the assumptions and basis to understand the pacts and signed partnerships, and how we can contribute. And then, we were put in the circle to discuss how we can contribute, what was the discourse of their initiative and propositional attitudes were also highly encouraged". (MS, representative of the community group Crisis and Covid-19 Human Rights Observatory).

"[...] that's why it was interesting to have contact with this line of work that Cidacs developed because it first excelled in listening. He had a system, which we recognise is of infinite importance, but he was concerned about listening and that integrates realities". (LG, representative of the community group Black Women's Group Mãe Andrea)

"[...] this is fundamental because the academy alone cannot have a perception of how society is doing" (FF, representative of policymaker from National Council of Health Secretaries).

Some impacts can also be highlighted due to public engagement work implemented in IDS-Covid-19. Three webinars and a lecture on topics related to the survey were held and opened to external audiences to survey participants. Researchers from universities and research centres, members of government institutions, health professionals, representatives of NGOs, community groups and journalists from different parts of the country attended these events, followed the process of building the Index, made suggestions and sent comments to inform the discussion. The audience present at

the Zoom events was 512 people, with another 1183 views on Youtube happening synchronously and asynchronously, since the material remains available.

Journalists were also important intermediaries for the massive transmission of information obtained through the IDS-Covid-19 on the effects of social inequalities in the pandemic. Around 140 news stories about the Index were published on websites, printed newspapers, radio and TV stations after its pre-launch, with a group of 11 journalists involved in sending of the press release to more than two thousand press professionals. It was possible to observe that both local and national media equally explored the data produced by the research in their reports.

Our initiative has increased the profile of public engagement issue in the scientific environment, as it was the subject of national and international congresses and meetings such as International Population Data Linkage 2022, The Global Health Network Conference, Abrascao 2022 and London School of Hygiene & Tropical Medicine week programme, when representatives of our team presented our results for British researchers. In addition, one of the representatives of community groups who participated in the engagement process, from the Black Women Network of Pernambuco, presented the Index and the interactive panel during the III Meeting of the Antropo-Covid Network at PPGA/UFPB, the scientific event about Covid-19 in a post-graduation course about Anthropology at the Federal University of Paraiba in the northeast of Brazil.

It is important to point out the relevance that the issue of public engagement in science had at Cidacs. A network group has since been established to debate and implement an ongoing engagement policy. In addition, other research projects under development and new research initiatives have been incorporating public engagement concepts and methods into their work. This experience with IDS-Covid-19 has also been shared with international South-to-South partners through The Data Science (DS) GC community mini-grant.

Conclusions

The dialogue was the central strategy of the public engagement of science during the construction of the IDS-Covid-19 because it supported values such as transparency, respect and ethics in the project. Throughout the process, the challenges, methodology, plans, limitations, and implemented solutions were shared between participants and researchers. In this way, an environment of collaboration and commitment was formed and supported the entire engagement process.

Public engagement in IDS-Covid-19 was the first systematic initiative of a research project carried out at Cidacs aimed at incorporating social participation during the research process. This process can be summarised in a few lessons learned: a) build in flexibility to explore the full range of knowledge, information and experiences of all participants; b) preparation by the research team ahead of all engagement events is crucial c) availability and empathy to openly discuss the project with the different segments of society is key; d) accessibility in the language to facilitate the understanding of the messages by the participants is also key; e) continuous

evaluation is required to adjust communication activities and products.

Some limitations of this work were the short period of time available to develop the strategies of public engagement, the impossibility of face-to-face activities with participants at the beginning of the project, and the lack of community representatives from the Brazil Midwest. The next steps involve continuing the relationship between Cidacs researchers and participants in the construction of IDS-Covid-19 for scientific dissemination processes, as well as for new projects that are in progress. Cidacs also seeks to promote the theme of public engagement with science in the Brazilian and international scientific community, to establish partnerships and share solutions in new research projects. These future works will have improvements like presential meetings with participants, and more diversity of groups and communication pieces. Besides that, Cidacs is developing new studies about the specificities of public engagement to promote population data science in a Global South country.

Statement on conflict of interest

The authors have no declarations of interest.

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Ethics statement

This study did not require ethical approval since it was based on our public engagement and involvement experience.

Author contributions

All the authors participated equally in the paper, collecting and analysing the data, as well as writing the paper.

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