PATHFINDER BRIEF

VACINA MARÉ

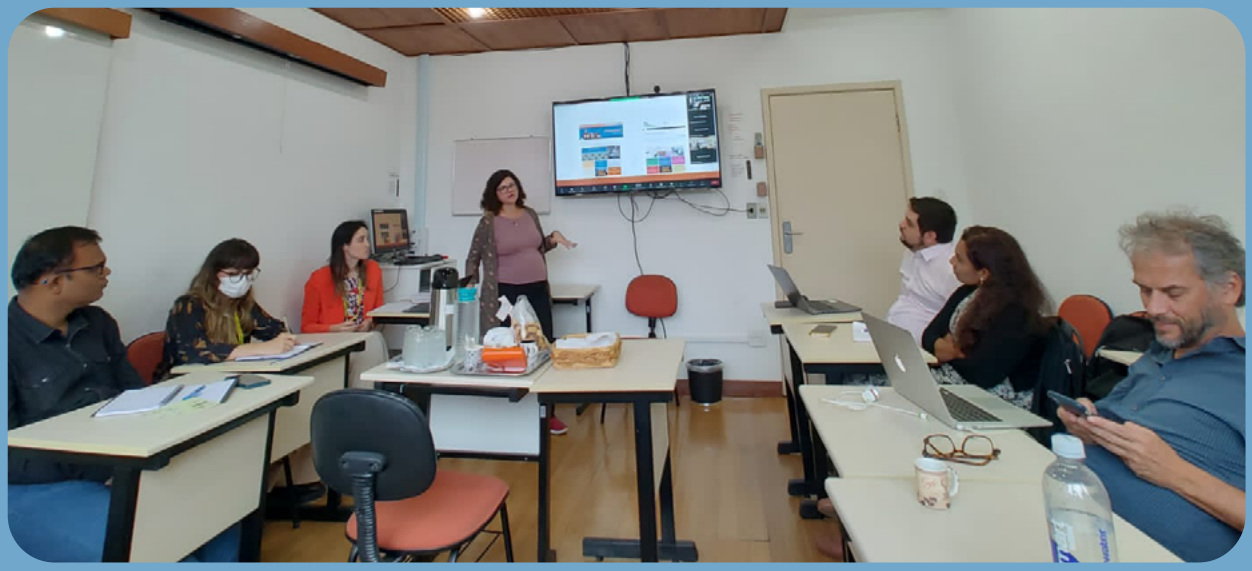
CHALLENGES, SOLUTIONS AND LESSONS LEARNED

doi.org/10.48060/tghn.170

Pathfinder, a study based on a research project, uses a methodological approach that maps key stages and indicators, supports the identification of obstacles and solutions, and captures and shares tools and methods adopted by the project. The Vacina Maré Research was selected for **Pathfinder** as a successful example, with significant impacts on collective health and the community, as well as addressing community and scientific issues collaboratively. Mapping the research allowed challenges and solutions to be identified, with valuable lessons for other projects as well.

1. PATHFINDER: DATA-DRIVEN PROCESS MAPPING FOR CAPACITY BUILDING IN RESEARCH

Pathfinder is a study based on a research project (called a host study) that uses a methodological approach based on processes mapping of research cycles, helping other projects, especially those built in under-resourced research environments, to draw tools, solutions and lessons learnt from exemplary studies. **Pathfinder's** objectives involve:



20 October 2023 - Face-to-face workshop “Tools to promote engagement and mobilisation in public health (Brazil, India and Malaysia)”.

i. identifying and recording the component steps necessary for the success of the host study;

ii. tracking the key indicators, such as time spent and resources required, for each component step to generate a process map;

iii. supporting the host study in identifying obstacles and finding solutions that enable the research objectives to be realised; and

iv. capturing and sharing the tools, methods, technology or governance processes used to solve each challenge.

The Vacina Maré Research was selected for the **Pathfinder** study due to its success in the pandemic context in a vulnerable territory, along with the valuable lessons with transformative potential and the scale of its results that go beyond the scientific publications produced from the data collected during the studies. The research achieved indirect impacts, both for public health and for the territory in which it was carried out, and this made the research innovative and exemplary, pioneering in community engagement and developed with residents and social organisations for action; allowing the distance between the scientific community and the Maré[1] community to be shortened, since the research was oriented with and for the people involved.

1. Maré, located in the North Zone of Rio de Janeiro - Brazil, is a group of 16 interconnected favelas with a dense population of around 140,000 inhabitants. It is strategically located between important access routes to the city, but despite its favoured location, the region faces challenges such as precarious infrastructure, overcrowding and the presence of armed civilian groups operating in the area.

The "Vacina Maré Research" was mapped in 2023 using a tool called "tracker". It consisted of documents, rounds of conversations and individual semistructured interviews with key players. The information collected was systematised based on activities related to the categories of **stakeholder engagement, research planning, data management and access, data analysis, outputs and impacts**.

During this qualitative information gathering, it was possible to identify the skills, tools, challenges, solutions and lessons learnt from and within the research process. These results will be presented as recommendations that can be useful for the host study and other research projects with similar objectives and locus of study.

Learn more about the **Pathfinder** methodology **here**.

20 June 2023 - TGHN LAC/Fiocruz team in a meeting with the Principal Investigator (PI) of the host study Vacina Maré.

2. CONTEXTUALISING THE VACINA MARÉ RESEARCH

The Vacina Maré Research is an initiative of Fiocruz, in partnership with Redes da Maré and Rio City Hall, with the primary objective of estimating the vaccine's effectiveness against COVID-19 and the impact of the pandemic on the Maré territory. The effect of the COVID-19 pandemic on vulnerable populations and weakened health systems has deserved global attention. The health crisis has exacerbated poverty and inequality, especially in communities like Maré in Rio de Janeiro. It was noted that the Brazilian government faced significant challenges in coordinating the response to the pandemic and mitigating its effects on communities.

Maré, a community with limited resources, faced the pandemic in a challenging context. Hunger, unemployment and a lack of adequate housing contributed to a lethality rate higher than the state average. The scarcity of effective public policies further aggravated the situation. Given this panorama, **Redes da Maré**, a community-based organisation that has been working for over 20 years to guarantee and expand the rights of Maré residents, implemented the "*Maré Says No to Coronavirus*" campaign as an emergency measure. As a result of this action and **Fiocruz's** long-standing relationship with the Maré territory, partnerships were strengthened with other social organisations (residents' associations, schools, health units, businesses, among other NGOs) that made the "**Health Connection**" project possible. This project ran from June 2020 to March 2022 and consisted of four significant free actions to combat COVID-19: testing, remote health care, support for safe isolation and communication and articulation actions in the territory.

The widespread territorial mobilisation in the context of COVID-19 and the reduction of contamination rates and disease lethality in the Maré territory enabled the mass vaccination campaign called "VACINA MARÉ" which brought forward the vaccination calendar against COVID-19 achieving a **high vaccination coverage**.

94,4%

of the adult population immunised with the two vaccine doses

Alongside the vaccination campaign, a series of scientific studies began, forming the so-called Vacina Maré Research, comprising three central studies. The results and findings of the research are part of a global investigation into vaccination, disease variants and post-covid effects (Long Covid). The Todos pela Saúde Institute (ITpS), the Center for Disease Control (CDC/Atlanta), the Wellcome Trust, the partnership with the University of Oxford and the ISARIC Consortium supported the research. It is also part of EFFECT-Brazil - one of the ten projects selected from more than 400 proposals from different countries around the world by ICODA (International Covid-19 Data Alliance), an initiative of the Bill and Melinda Gates Foundation.

Study 1. Vaccine effectiveness and new variants

OBJECTIVE
Identifying the effectiveness of the AstraZeneca vaccine in reducing COVID-19 infection in Maré, determining the levels of protection against new variants and the vaccine's effectiveness, and considering booster doses.

TARGET AUDIENCE
Maré residents vaccinated with at least one dose against COVID-19 and unvaccinated residents.

STUDY DESIGN
Negative case-control test.

OUTPUTS
People vaccinated with the first dose developed 31.6% protection against COVID-19 after 21 days of immunisation and 65.1% protection after 14 days of immunisation with two doses.

Study 2. Cohort studies with families from Maré

OBJECTIVE
To evaluate the clinical, epidemiological and genomic profiles, as well as the effects of COVID-19 in Maré, including immunological protection and virus transmission. The study analysed COVID-19 seroprevalence, disease burden, and associated socioeconomic factors.

TARGET AUDIENCE
Families living in Maré who voluntarily took part in the study.

STUDY DESIGN
A cohort study to evaluate the proportion of infected people among the vaccinated and unvaccinated (seroprevalence).

OUTPUTS
Started at the same time as study 1. Population cohort study consisting of five stages of data collection (approximately 6-month intervals) monitoring COVID-19 in the territory (levels of infection and protection), the study collects important information about the health of part of the Maré population (cross-referencing with other diseases, comorbidities, mental health and profile of use of primary care services, among others.

Study 3. Consequences after COVID-19 (Long Covid)

OBJECTIVE
To evaluate the physical and mental health consequences in Maré residents who tested positive for COVID-19 and developed the disease whose symptoms were persistent.

TARGET AUDIENCE
Maré residents who tested positive for COVID-19, between vaccinated and unvaccinated.

STUDY DESIGN

Based on questionnaires administered to more than 800 residents who tested positive for COVID-19, the study analyses the frequency of Long COVID and its main symptoms, risk factors and impact on quality of life.

OUTPUTS

Frequency of Long COVID (a disease already recognised and classified by the World Health Organisation), main symptoms, risk factors and impact on quality of life are some of the characteristics evaluated by the study.

An important and central aspect that characterises the “Vacina Maré Research” is the shared governance, where various initiatives, partnerships and actors come together to meet local studies and demands, with specificities and particularities that require the consolidation of work fronts. To this end, it was necessary to set up several teams, as well as a central coordinating body under the responsibility of the Principal Researcher. The field team was responsible for territorial articulation and collecting personal and laboratory data. A team was also responsible for data to establish how to collect, store and analyse the material collected. In addition, a communications team was needed to strengthen community engagement.

31 July 2021 - Launch of the Maré Vaccine Campaign and Research with representatives from the public authorities, Fiocruz, Redes da Maré and the research team.

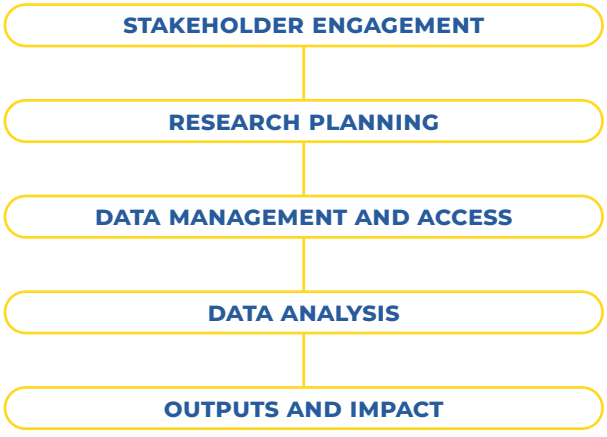
Although there were specific teams assigned to each stage/action of the studies (for example: field team - liaisons and community health agents and nursing technicians; data team; coordination; stakeholders; researchers; among others), there was no hierarchy of knowledge and functions, with the understanding that everyone involved in the research process had essential and complementary expertise, which was recognised and valued both for evaluating and monitoring the process and for producing the analyses and results of the studies. This shared, articulated and horizontal management allowed for shared governance that ensured the successful performance of the Vacina Maré Research and was undoubtedly a differentiator in producing data with the community, generating actions with a direct and indirect impact, as we will see next.

3. IDENTIFYING CHALLENGES, SOLUTIONS AND LESSONS LEARNT

Pathfinder, as a study based on the mapping of research stages, aims to strengthen and accelerate the fields of health science and data sharing, and can give visibility to experiences, learnings and solutions in an organised way, improving the technical capacity of the host study team and other similar studies.

19 July 2023 - Workshop on "Qualitative research methodology" with the Pathfinder teams from Vacina Maré and Birth in Brazil II.

The main challenges, solutions and learnings identified through the qualitative research carried out between June and November 2023 with the "Vacina Maré Research" team are listed as follows. The results of this qualitative mapping, based on document analysis, roundtables discussion and individual interviews, were systematised using the tracker, and presented next according to the categories of the tracker tool.



Vacina Maré Pathfinder Categories

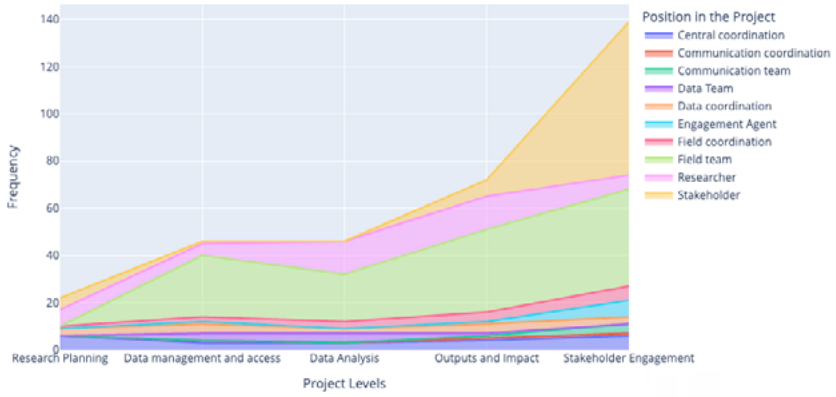
Stakeholder engagement

The "stakeholder engagement" category covered various challenges and solutions related to mobilising the community and strategic institutional partners, effective communication, legitimising the research process and maintaining the engagement of voluntary research participants. In the Vacina Maré Research, the engagement actions were structural. They had already been taking place before the project began and continued throughout all the stages, so we consider this category to precede the research planning. They comprise specific practices to involve stakeholders, such as communication actions (brand logo, sound car, flyers, door-to-door, publicity items), meetings, workshops and public consultations. Ongoing evaluation monitors effectiveness and identifies areas for improvement.

Research planning

Mapping out the activities performed for "research planning" took us through several interconnected stages. Initially, it was crucial to identify the central questions of the studies and the relevant data sets. Next, it was necessary to learn about the process of obtaining approval from the Ethics Committee in order to ensure that the studies could be carried out while assessing the impact of the study. Mobilising partnerships and applying for funding occurred throughout the studies, which required presenting the objectives, methods and potential contributions. Also, during the "research planning" phase, the team formation, skills and tools needed for the studies were identified. To summarise, the research protocol covers everything from formulating the question to planning teams and resources, identifying data, obtaining ethical approval, seeking funding and evaluating

Number of agents according to position and step of the Vacina Maré Research



impact.

Data Management and Access

In " Data Management and Access ", there was the process of developing a comprehensive plan for efficient data management during the project. This includes strategies for securing data collection, storage, processing and sharing. By implementing policies and standards, data governance considerations ensure integrity, quality, and security. Data capture and collection refer to obtaining the information needed for research using various sources. Grouping, curation, cleaning and preparation are essential steps to organise and guarantee the quality and reliability of data.

Data Analysis

In the "Data Analysis" category, we sought to learn about the process of creating the plan for guidance and analysing the data during the project, including strategies for choosing statistical models and exploratory analysis. Exploratory analysis is crucial for identifying data patterns, trends and preliminary relationships. The choice of appropriate statistical models was a fundamental stage involving the careful selection of statistical techniques that meet the study's specific objectives. The emphasis on the proper choice of models was reiterated to guarantee the results' validity and the most appropriate interpretation.

Outputs and Impact

By "Outputs and Impact" we mean both the publication plan's development and the dissemination of research results. In addition to preparing scientific publications, the production of other resources for communication and dissemination of study results was mapped. It was essential to consider the indirect results to assess the implications of the research, which involved analysing the effects, not only in the academic sphere but also in terms of practical applicability, public policies and potential contribution to the residents of Maré and society in general.

STAKEHOLDER ENGAGEMENT

CHALLENGES

- Resident mobilisation on the importance of COVID-19 vaccination.
- Ineffective communication from academics and the government, leading to the spread of misinformation and fake news.
- Staff turnover impact makes it difficult to build a bond with participants.
- Technical issues with the hardware for registration and data collection.
- Communicating complex research with a broad audience.
- Limited resources and lack of dedicated communications, engagement and mobilisation teams.
- Keeping volunteer research participants engaged in the study cycles after the vaccination campaign.

SOLUTIONS

- Mobilising a range of different actors, including Redes da Maré workers, volunteers, residents and community associations.
- Promoting community engagement through local teams.
- Combating fake news through social media and by engaging local influencers.
- Establishing standardised communication methods, including a visual identity, using simple, direct and effective communication.
- Production and distribution of items with the project's visual identity (e.g. bags, t-shirts, squeezes and cards) to Maré residents who volunteer for the studies.
- Holding regular meetings with teams and stakeholders to evaluate, monitor and plan new mobilisation actions, adapting strategy based on feedback.
- Periodic feedback to keep those involved active and engaged.
- Providing continuous capacity building and training.

LESSONS LEARNED

- Building trust and long-term relationships with the community was pivotal in the success of the project.
- Engaging stakeholders throughout the process empowered community members to drive change and take ownership of initiatives. Shared and horizontal management.
- Effective communication and feedback mechanisms foster transparency and progress.
- Communicating the research to the territory without the territory being seen only as a field for scientific experiments, but as collaborators of the research process, helped to legitimise the research process in a positive way for residents.
- Knowledge sharing across disciplines highlights the value of diverse perspectives in addressing community challenges.
- Political alliances and interdisciplinary collaboration drive community initiatives.
- Understanding the local reality and adapting communication and engagement strategies based on the experience of the field team.
- Community engagement and mobilisation as a social technology developed and improved over time.
- Persistent and constant action is essential for changes in the medium and long term.

RESEARCH PLANNING

CHALLENGES

- Limited time and urgent research, ethical and bureaucratic demands amidst pandemic urgency.
- Difficulty in locating qualified personnel for data collection, curation, and management.
- Lack of management tools.

SOLUTIONS

- Focus on participative collaboration for development of the research protocol.
- Expedited ethical approval.
- Collaboration with financial backers and key stakeholders.
- Training initiatives with field teams and scholarship student engagement in data curation for research activities.
- Coordination with family clinic managers to identify community health workers.

LESSONS LEARNED

- Community relationships and stakeholders enhanced collaboration for research planning and implementation.
- The focus on the rapid development of plans helped mitigate limited time ranges and solve urgent research demands.
- The provision of continuous training of the team in data collection, curation and management helped to overcome the complexity of the research process.
- The coordinated work with managers of the family clinics made it possible to identify community agents for the composition of the research field team.

18 August 2023 - Roundtable discussion on “Research Planning” with the Vacina Maré host study team.

DATA MANAGEMENT AND ACCESS

CHALLENGES

- Lack of formal documentation for data management.
- Limited resources and infrastructure for establishing effective data management and a secure data environment.
- Challenges in managing and processing large datasets from diverse sources and formats.
- Need for awareness and adherence to data governance practices.
- Inexperienced field researchers impacting data reliability.

SOLUTIONS

- The Vacina Maré and DP-EFFECT-BRAZIL projects formalised data management policies within research protocols.
- Provision of training in data collection. Engaging with the community and field researchers improved data collection processes. Publicising partial data incentivised community participation and improved data accessibility.
- Transparent communication on data privacy, handling and sharing to create trust.

LESSONS LEARNED

- Flexibility in response to evolving demands of the pandemic ensured effective data management strategies.
- Implementation of specific data governance policies upheld legal frameworks and ethical standards.
- Knowledge of the social context enhanced data consistency and collection practices.
- Ongoing training improved data management skills and expertise and facilitated adaptation to current data governance standards.
- Collaboration between teams enriched knowledge and study outcomes and improved data quality through complementary efforts.

DATA ANALYSIS

CHALLENGES

- Short timeline for developing analysis plans.
- Delays in sharing secondary datasets.
- Adjusting analysis methodologies to evolving study parameters.
- Defining specific criteria for conditions like Long COVID.
- Ensuring consistent team collaboration and communication.
- Lack of experience with big data analysis, epidemiology and vaccine efficacy modelling.
- Inadequate/incomplete execution of the data collection, collation, curation, and cleaning activities in the first stage of the research.
- Changes in data collection cycles.
- Participant dropout in the study.

SOLUTIONS

- Regular meetings to improve team engagement.
- Partnership with specialists to help with technical training and proposals for analysis models (data curation and analysis).
- Implementing mechanisms for timely data sharing.
- Allocating an exclusive team for data analysis.
- Flexibility to adjust analysis plans based on evolving study dynamics.
- Implementing bias correction methods for non-responsive samples.
- Choosing specific criteria, like the persistence criterion, for analysis.

LESSONS LEARNED

- Involving experts enhances study quality.
- Keeping an eye on similar studies aids in refining methodologies.
- Forming a diverse team with varied technical skills improves analysis quality.
- Providing structured training enhances the team's analytical capabilities.
- Bringing the analysis team closer to the field team to get to know the local reality helps to improve the accuracy of results.

RESULTADOS E IMPACTO

CHALLENGES

- Absence of a specific budget for producing publicity materials and disseminating results to the grassroots.
- Absence of specific expertise for conducting cohort studies.
- Limitations in health infrastructure and equipment for the vaccination campaign and cohort studies.
- Lack of trust and credibility in local health centres among residents.
- The challenge of communicating complex issues in an accessible way.
- Maintaining the mobilisation of the residents participating (volunteers) in the research through communication.
- The field team's lack of experience in scientific research, given the importance of preserving most residents.

SOLUTIONS

- Regularly updating and adapting communication materials based on the research data and results.
- Conducting meetings between coordinators and teams to align and prepare publicity materials.
- Providing training and information to the field team, who serve as the main dissemination team, to effectively communicate about the research.
- Raising funds and allocating resources to improve infrastructure and equipment at health centres in Maré, increasing their visibility and accessibility to residents.
- Field team made up of Maré residents.
- Partnership with health centre managers to include Community Health Workers in field teams.
- Multidisciplinary team in constant exchange, including different professionals and external specialists.
- Dissemination and validation of results (partial and final) with residents and stakeholders.

LESSONS LEARNED

- The publication of scientific articles with international repercussions has increased the visibility of the research results.
- The Vacina Maré Research not only had an impact on collective health, but also transformed data into actions to improve the quality of life of residents, thus promoting community engagement for health equity.
- Shared, horizontal governance and intersectoral coordination facilitate team integration and agility in responding and adapting to dynamic demands.
- The wide repercussion of the positive results of the studies has made the Maré favela more visible (locally and nationally) and has promoted the valorisation of the territory, beyond its vulnerabilities.
- The participation of Community Health Agents in the field team made it possible for the study to access some families who were already being followed up by the family clinics. On the other hand, other families who volunteered for the study and who were not being looked after by the health unit were now linked through the research field team.

RESULTADOS E IMPACTO

APRENDIZADOS

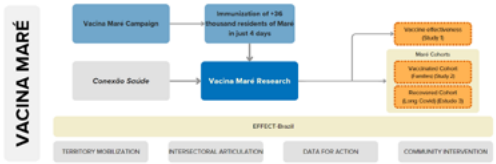
- Understanding that knowing the reality is fundamental to the success of the project.
- The importance of simple, direct and effective communication, both between the team and with the community. Also, disseminating and validating study results with the community and stakeholders, favouring engagement.
- Scientific studies must be linked to local reality and demands. It is possible and necessary to involve favela residents in the construction of scientific knowledge.
- Deconstructing the idea of a researcher being limited to academia and laboratory settings. When research is carried out with the contribution of the favela and the streets to scientific knowledge and alongside the community, it is more relevant, and the health actions are more effective.

FINAL CONSIDERATIONS

The Vacina Maré Research faced significant challenges, from mobilising residents to vaccinate against COVID-19 to managing data and disseminating results. However, solutions such as strengthening communication, continuous team training and community engagement were key to overcoming these challenges. Collaboration with stakeholders and building trust with the community were essential, emphasising the importance of transparency, effective communication and constant adaptation to the needs and demands of the pandemic. The impacts of the research go beyond collective health, transforming data into concrete actions to improve residents' quality of life and promote health equity, demonstrating the relevance of linking scientific studies to local realities and involving favela residents in the construction of scientific knowledge.

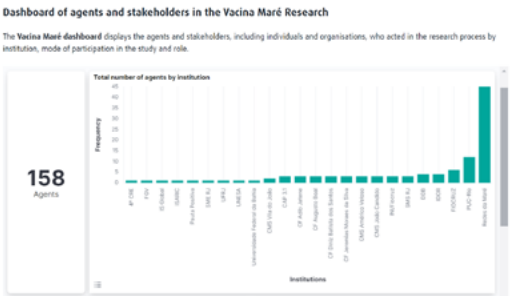
The moments promoted by **Pathfinder** for mapping the research through document analysis, roundtables and interviews triggered a process of individual and collective evaluation among the team members, recognising the complexity of the study, but also realising the great effort and success of the investigation, which during the pandemic, in a context of vulnerabilities, offered lessons and transformative results. In addition to the great reflection provided by **Pathfinder**, other support materials have been produced, not only for the team, but also for developing research capacities for other studies.

Vacina Maré Pathfinder Productions

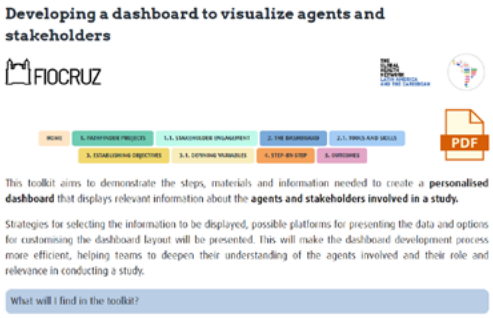


Mind map and **timeline** of the Vacina Maré Research

Process map of the Vacina Maré Research



Pathfinder Dashboard: agents and stakeholders of the Vacina Maré Research



Toolkit **building the Pathfinder Dashboard in Kibana**

Pathfinder Brief **VACINA MARÉ: challenges, solutions and lessons learned**

Toolkit "**Qualitative research methodology for the Pathfinder tracker**"

In-person workshop "**Tools to promote engagement and mobilisation in collective health (Brazil, India and Malaysia)**"

Webinário "**Introduction to R for health data Science**"

Toolkit "**Favela and science: how to do research in peripheral territories**"

Data reuse - Article "**The impact of the first year of COVID-19 vaccination strategy in Brazil: An ecological study**"

For more details, click here.

REFERENCES

[1] Ranzani, O. T., Silva, A. A., Peres, I. T., Antunes, B. B., Gonzaga-da-Silva, T. W., Soranz, D. R., ... & Bozza, F. A. (2022). Vaccine effectiveness of ChAdOx1 nCoV-19 against COVID-19 in a socially vulnerable community in Rio de Janeiro, Brazil: a test-negative design study. *Clinical Microbiology and Infection*, 28(5), 736-e1.

[2] Batista-da-Silva, A. A., Ranzani, O. T., de Paulo, D. M., Braunstein, M. L., Bozza, H. R., Fischer, R., ... & Bozza, F. A. (2023). Maré cohort-profile: a prospective cohort study based in a socially vulnerable community during the COVID-19 pandemic in Rio de Janeiro, Brazil. *Gates Open Research*, 7(22), 22.

[3] Fischer, R., Bozza, B., Victorino, C., Motta, M., Arouca, L., & Bozza, F. A. (2022). What did you do to stay 'sane' during the pandemic? A qualitative study to identify self-care mental health strategies utilized in a socially vulnerable population. *Gates Open Research*, 6(79), 79.

CREDITS

Produced by:

Laís Martins Costa Araujo (Fiocruz, TGHN LAC)
Soraida Aguilar (PUC-Rio)
Larissa Pruner Marques (Fiocruz, TGHN LAC)
Letícia Marinho (Fiocruz, TGHN LAC)
Flávia T. Costa Bueno (Fiocruz, TGHN LAC)
Fernando Bozza (INI, Fiocruz)

Collaboration:

Fiocruz Pathfinder Team

Cristiani Vieira Machado
Vanessa Arruda Jorge
Luciana Monteiro-Krebs
Vitor Villaça
Luisa Picanço
Contact: fiocruz.tghn@fiocruz.br

Vacina Maré Research Team

Fernando Bozza (PI)
Luna Arouca (Redes da Maré)
Everton Pereira (Redes da Maré)
Carolina Dias (Redes da Maré)
Luciana Bento (Redes da Maré)
Henrique Gomes (Redes da Maré)
Diana Souza (Redes da Maré)
Grazielle Viana (IDOR)
Amanda Batista (PUC-Rio)
Leonardo Bastos (PUC-Rio)
Silvio Hamacher (PUC-Rio)
Thiago Wendel
(coordenador CAP 3.1/SMS-RJ)

Health Data Science (HDR) Global

Agklinta Kiosia
Sally Boylan
Matthew Retford
Anne Wozencraft

Graphic Design and Layout:

Paulo Nery

Photo

© Douglas Lopes
Gabi Lino
https://flic.kr/s/aHsmWgkB9u

Araujo, L. M. C., Aguilar, S., Marques, L. P., Marinho, L., Bueno, F. T. C., & Bozza, F. (2024). Technical Report: Pathfinder Vacina Maré – challenges, solutions and lessons learned. Fiocruz/TGHN LAC. Available at: https://doi.org/10.48060/tghn.170.

FIOCRUZ

THE GLOBAL HEALTH NETWORK
Enabling research by sharing knowledge

THE GLOBAL HEALTH NETWORK LATIN AMERICA AND THE CARIBBEAN