

Title **0083**
by **Monica Malta** in **Inclusive Health Research**
2024

Original Submission

Score n/a

1. The Entry

1 1. Lead organisation or Institution chiefly responsible for submitting this entry University of Toronto

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1.2 Chief Contact Person Monica Malta

Chief Contact Person's Job Title/Post Assistant Professor

1.3 Name of project or programme	RISE: Resist, Intervene, Support, Empower
1.4 Date that the project or programme began	01-September-2020
1.5 Countries in which research / implementation was undertaken	Brazil
1.6 About partners and collaborators	Here you should name up to three collaborating organisations and provide a contact email address for each one that you name. We will then send a request for a supporting statement, which will be taken into account in the scoring of this application.
Partner organisation/institution #1	Oswaldo Cruz Foundation, Brazilian Ministry of Health
Type of Organisation	Academic/research institution
Website URL	https://portal.fiocruz.br/en
Partner organisation/institution #2	Brazilian National Transgender Association (ANTRA) and Brazilian National LGBTQ+ Association (ABGLT)
Type of Organisation	Patient Advocacy Organisation
Website URL	https://antrabrasil.org and https://www.abglt.org
Partner organisation/institution #3	Micro Rainbow International Foundation - Brazil
Type of Organisation	Patient Advocacy Organisation
Website URL	https://microrainbow.org

The Case Study

1.8 The Title of Your Case Study	RISE Study ("Resist, Intervene, Support, Empower"): Addressing the impact of violence among queer women from Brazil
1.9 Simple Summary	Femicide, the intentional killing of women because of their gender, is a pervasive global issue, particularly pronounced in Latin America, where rates have seen a notable surge in recent times. Brazil stands at the forefront of this troubling trend, with racialized and queer women bearing a disproportionate brunt, highlighting the intersecting layers of discrimination. Despite legislative advancements, elevated rates persist, largely due to survivors' reluctance to report, fueled by fear and dependency on their perpetrators, exacerbated by inadequate prosecution and conviction rates. The criminal justice system grapples with legislative gaps, lax enforcement, and discriminatory practices, eroding trust and perpetuating cycles of underreporting and impunity. To address these challenges, RISE—a mobile app—was collaboratively developed with affected communities, providing survivors with a remote reporting platform and access to a comprehensive array of support services, including pro-bono legal aid, shelters, childcare, and mental health assistance, available round-the-clock.
1.10 Introduction	Over 50,000 female-identified persons are killed worldwide due to domestic violence. I survived it. In 1996, I made the courageous decision to leave my abusive husband after a decade of violence. However, my journey took another challenging turn when I received a positive HIV/AIDS diagnosis while pregnant that same year. Despite being told I wouldn't survive to raise my child, I defied the odds. Since then, my mission has been to stand in solidarity with women facing similar struggles. I worked in many low and middle-income countries, starting with my home country, Brazil. Today, as a professor and researcher, my commitment remains unchanged: to amplify survivors' voices, empower them, and collaboratively develop culturally sensitive interventions tailored to their unique needs. I led the RISE app development, with support from NIH, Canadian and Brazilian agencies. The successful strategy holds two patents, is freely accessible and supported by the Brazilian Ministry of Health. The app's development involved grassroots organizations like the Brazilian Lesbian Association, Brazilian Transgender Association, and MicroRainbow International, with guidance from Duke University experts. Every step, from development to testing and refinement, was undertaken hand in hand with individuals with lived and living experiences, ensuring its relevance and effectiveness.
1.11 Key Words	Brazil, Latin America, gender-based violence, domestic violence, intimate partner violence, mobile health, eHealth, LGBTQ, LGBT, LGBTQ+, sexual and gender minorities
Which category best fits this project or programme?	Addressing a specific unmet health need

2. Unmet Health Need Case Study

These will typically fall in to one of three groups: Group 1: Understanding needs and context Group 2: Designing and conducting research Group 3: Translating research into impact The various suggested sections which follow will not be equally applicable to all groups. We have given an indication of which sections may be most crucial to each but you should use your own discretion and judgement. We are seeking case studies that can be published, so please write your entry as summary, rather than a series of statements addressing the questions. You do not need to repeat information across sections. We do not expect everyone to be able to address all of the questions, as not all will be relevant.

2.1 Who should benefit from the project or programme? (Applicable to groups 1, 2, & 3)

Latin America and the Caribbean stand as regions of stark contradiction when it comes to the safety and rights of marginalized communities, particularly women and sexual and gender minorities (SGM). Despite being a cradle of vibrant cultures and landscapes, the region has become synonymous with some of the most alarming statistics on femicide and violence against the SGM community worldwide.

In this region, being a woman is perilous, with rates of femicide soaring ten times higher than the global average. Shockingly, over 12 women and girls are killed every day, yet a staggering 98% of these cases remain unprosecuted. Brazil, a leading figure in this grim narrative, shoulders over 40% of reported femicides in the region alone.

Additionally, Latin America and the Caribbean emerge as the most treacherous territories for SGM individuals, with nearly three-quarters of all registered murders of transgender and gender-diverse individuals occurring here. Since 2009, Brazil alone has witnessed a third of these tragedies. The plight extends further to lesbian and bisexual women who face endemic physical and sexual violence. Moreover, the burden is disproportionately borne by racialized persons and those grappling with socioeconomic disparities.

Despite strides in recognizing SGM's rights over the past decade, Latin America faces formidable barriers hindering further progress. Hundreds of hate crimes go unprosecuted amidst pervasive violence and discrimination. The average life expectancy of trans women in the region stands at a mere 35 years, a damning contrast to the general population's 80 years.

Experiences of discrimination and violence plague SGM individuals across various settings, from schools and workplaces to healthcare facilities and public spaces. Legal protections often elude them, while familial and communal rejection compounds their struggles. Alarmingly, violent crimes and hate incidents against SGM persons frequently go unreported and unpunished due to profound distrust between the community and law enforcement, exacerbated by persistent discrimination and harassment perpetrated even by the police.

In light of these harrowing realities, we developed a mobile health intervention devised to combat rampant violence against SGM individuals in Brazil, addressing structural issues that perpetuate underreporting and crime.

2.2. Engagement (applicable to groups 1, 2, & 3)

To develop the RISE app and effectively address the unique challenges faced by Sexual and Gender Minority (SGM) individuals in Brazil, a comprehensive community-based participatory research (CBPR) initiative unfolded between 2019 and 2020. We revised the study in collaboration with key SGM organizations in Brazil, including the Brazilian Lesbian Association, the Brazilian LGBTQ+ Association, the Brazilian Transgender Association, and MicroRainbow International. These collaborations formed the bedrock for the study's Community Advisory Board (CAB), comprising representatives from these organizations alongside other community leaders. Eleven diverse participants from the Brazilian SGM community were included in the CAB, ensuring a wide spectrum of perspectives.

Meeting monthly, CAB members engaged in an iterative process with the research team, delving into culturally nuanced recruitment strategies, protocol adaptations, and the interpretation and dissemination of research findings. Grounded in collective reflection and systematic inquiry, CBPR methodology fostered collaborative efforts between researchers and SGM stakeholders.

CBPR involved collective, reflective, and systematic inquiry in which researchers and SGM community members worked together in all steps of the research process. CBPR is a key methodology for bringing about social change and is particularly useful when working with highly marginalized populations.

Twenty-two focus group discussions were conducted with SGM persons from eight Brazilian cities: Belém, Aracaju, Rio de Janeiro, Niterói, Uberlândia, Brasília, Salvador, and São Paulo, including 300 SGM. Then, in-depth interviews were also conducted with a few key informants, most community leaders and professionals providing services for SGM persons experiencing discrimination/violence. The primary objective was to unearth actionable strategies to amplify the reporting of discrimination/violence incidents against SGM persons while facilitating access to comprehensive support services.

Subsequent to this intensive data-gathering phase, the app was meticulously developed and subjected to pilot testing by SGM community members. This cohort provided invaluable feedback, assessing aspects ranging from the clarity of educational content to the functionality and user-friendliness of intervention features. Their insights informed a rigorous review process, changes in colours, format, and icons, ensuring app's higher acceptability and perceived efficacy.

After a thorough pilot test, further rounds of review and feature tailoring ensued, culminating in the app's official launch in December 2019, poised to empower SGM individuals across Brazil in navigating and combatting discrimination and violence. Community partners are authors/co-authors of all publications, presented the study results locally and internationally, and continue to work with our team to develop knowledge dissemination and knowledge exchange strategies up to today.

2.3. The Research (Particularly relevant for groups 2 & 3)

We initiated our study with a comprehensive phase engaging over 300 SGM individuals living in diverse Brazilian cities. This inclusive approach encompassed urban metropolises like Rio de Janeiro and Sao Paulo, as well as harder-to-reach areas nestled within the Amazon Bay and rural hinterlands. This initial exploration, bolstered by our collaborative engagement with community stakeholders via the Community Advisory Board, shed light on the nuanced and pressing needs of Brazil's SGM community.

Our original vision was to develop an app empowering SGM individuals to report episodes of discrimination or violence directly, bypassing conventional avenues like police stations. These establishments are often viewed as unsafe places where other types of violence/discrimination occur. Our aim was to bridge the gap between underreporting and prosecution by facilitating online crime reporting.

The app features a Panic Button designed for emergencies, enabling users to swiftly share their location and contact details with five pre-registered emergency contacts. This feature, identified by users as literally life-saving, sets our app apart from generic personal safety and violence prevention applications, as it caters specifically to the needs of SGM individuals.

However, our initial research phase unearthed additional concerns that needed attention. Local SGM associations highlighted alarmingly high rates of suicide, suicide attempts, depression, anxiety, and post-traumatic stress disorder (PTSD) among SGM persons grappling with the daily onslaught of discrimination and violence.

The pervasive experiences of violence contribute to elevated levels of mental health disorders, often underrecognized and undertreated among SGM individuals from Brazil. Responding to this feedback, app users now have access to a personalized mental health screening plan. Users can report instances of violence/discrimination and also access mental health screenings, receive online support and treatment referrals to services already highlighted within the app as safe places for SGM patients. Those experiencing suicidal ideation or attempts are promptly connected to a 24/7 crisis line for immediate support.

RISE is a testament to the power of collaboration between SGM individuals, researchers and professionals serving this community in Brazil. Its prototype underwent rigorous testing and refinement based on community feedback led by Brazilian researcher Monica Malta, herself a queer woman survivor of domestic violence. Local NGOs and healthcare professionals played indispensable roles in its development and enhancement, contributing crucial expertise and perspectives. With the backing of the Brazilian Ministry of Health, RISE was scaled up and is making a difference in the lives of SGM individuals across Brazil.

2.4. Translating to Impact (Particularly relevant to group 3)

With support from the Brazilian Ministry of Health, the RISE app became a government initiative, formalized through registration with the Brazilian National Institute of Intellectual Property. Three patents were secured for this groundbreaking intervention: Rainbow Resistance: RISE App for Android, RISE for iOS, and RISE website, ensuring comprehensive accessibility across platforms. The RISE app is free and has over 10,000 active users as of February 2024.

As the user community expanded, localized strategies became imperative. Responding to heightened reports of violence in specific areas, partnerships were forged with local law enforcement agencies. In regions grappling with elevated rates of mental health disorders, the research team embarked on visits to local outpatient units, delivering tailored training sessions on SGM Health, Diversity, and Inclusion.

Data derived from the RISE app have been instrumental in informing policy advocacy efforts at local government levels, informing NGO reports, and shaping community presentations aimed at advocating for improved strategies to address the distinct needs of SGM individuals across diverse Brazilian cities. Recognizing the critical importance of lived/living experiences, individuals with firsthand insights have been granted full access to the study dataset, with many being recruited into the research team. Regular training sessions are organized to empower local NGOs in leveraging research data and findings to enact meaningful change within their communities.

In Brazil, SGM individuals contend with a multitude of socio-economic challenges, including elevated poverty rates, low educational attainment, lack of familial support, and limited job opportunities. Transgender and non-binary individuals are disproportionately affected, often compelled into precarious or informal employment. Many grapple with homelessness at some point, exacerbating their vulnerability to violence and perpetuating cycles of poverty and marginalization.

In response, a partnership was established with the Micro Rainbow International Foundation, offering small business training to low-income SGM entrepreneurs. Tailored support, financial management training, and assistance in business establishment were provided, leading to significant business expansions and new ventures. Participants reported increased self-confidence and reductions in mental health issues, illustrating the transformative impact of economic empowerment in navigating discrimination and marginalization.

This community-based participatory approach underscores the importance of collaboration between researchers, healthcare professionals, government representatives, and individuals with lived/living experiences. By centring community input and tailoring interventions to local needs, culturally sensitive solutions can be developed to empower marginalized communities effectively. In navigating these endeavors, humility and respect for the motto "Nothing about us, without us" remain highly important.

2.5. The Future
(Applicable to groups
1, 2, & 3.)

To explain my future plans, it's crucial to reflect on a defining moment from the past. In 1996, after enduring a decade-long marriage marred by daily violence, I made the courageous decision to divorce. Against all odds, I survived. Yet, in light of the millions of female-identified individuals who tragically do not survive such violence, I am compelled to use my voice and resources to empower local communities. Recognizing the absence of survivor voices in most interventions addressing gender-based violence, my aim is to reshape this narrative by centering community input and participation.

Securing funding to enhance the RISE app is a priority. In Brazil, I would like to engage transgender women in the Amazon Bay, lesbian and bisexual women in rural areas, and gay, trans, and bisexual men across rural and urban settings to tailor the app to their specific needs. This includes language adaptations, refining questions, and expanding our network of local partners. The goal is to ensure the app authentically resonates with each community it serves, with individuals with lived experiences leading the way.

In parallel, I also believe that we need to amplify interventions aimed at breaking the cycle of poverty among SGM individuals, partnering with organizations like the Micro Rainbow International Foundation. Research consistently demonstrates that SGM individuals and their families face higher economic struggles, including elevated rates of poverty, housing instability, and food insecurity. Multiple factors contribute to these challenges, including ongoing discrimination in various aspects of daily life, from education to employment and housing. Initiatives such as the ones we implemented in Brazil provide tangible opportunities for SGM individuals to overcome poverty's constraints and build brighter futures.

Expanding the RISE app's reach to other Latin American countries facing high levels of discrimination and violence against SGM individuals is another goal. However, this is not only a matter of translating an existing app developed in Brazil. It requires a ground-up approach, working closely with local communities to tailor the app to their unique needs and perspectives. Collaboration with SGM individuals in countries like Colombia or Argentina demands fresh insights and substantial financial support.

Ultimately, our aim is to empower local communities. Ideally, this ambition would extend to eradicating violence and discrimination based on gender identity, expression, and sexual orientation altogether. Through our collaborative efforts, we strive to create a world where every individual, regardless of their identity, can live free from fear and prejudice.

4. The Prize Fund	I would start by working closely with grassroots organizations to improve the existing RISE app, building local capacity at the core organizations working with SGM persons in Brazil: Brazilian Lesbian Association, Brazilian Transgender Association and Brazilian LGBTQ+ Association. Collaborating with the Micro Rainbow International Foundation, we aim to bolster their tailored training programs designed for SGM individuals living below the poverty line in Brazil. To enact these plans, I propose allocating seed funding to each organization or pooling resources collectively while facilitating the hiring of representatives from each organization and individuals with lived/living experiences.
5. Your advice to others	Based on my own experience, I would advise others aspiring to undertake similar work to prioritize community engagement and collaboration from the outset. Ensure that the voices and perspectives of those directly impacted by the issues being addressed are central to every stage of planning and implementation. Additionally, foster strong partnerships with grassroots organizations and leverage their expertise and networks to maximize impact. Stay adaptable and open to feedback, continuously refining strategies based on the evolving needs of the community. Finally, prioritize sustainability by building local capacity and empowering community members to lead and sustain initiatives long-term.
6. Supporting Evidence	
6.1. Funders	<p>NIMH/NIH (Grant # 5R21MH119496-02), period 01-September-2020 to 31-July-2024 Title: RISE Study ("Resist, Intervene, Support, Empower"): Feasibility/Acceptability of MHealth Intervention targeting Transgender Women facing gender-based violence and mental health disorders in Brazil (Budget 339,158 USD / 268021 GBP) Link: https://reporter.nih.gov/search/7vNQkV4p7Ea_M5hDm9qCIQ/project-details/10237170</p> <p>Grand Challenges Canada (Grant # R-ST-POC-19090-30854), period 30-September-2019 to 30-September-2022 Title: RISE Study-"Resist, Intervene, Support, Empower": Addressing violence against lesbian, bisexual and transgender women from Brazil (Budget 100,000 CAD / 58,179 GBP) Link: https://www.grandchallenges.ca/grantee-stars/1909-30854/</p>
6. 2. Academic/Professional Publications	<p>Malta M, Kalume C, Ribeiro I, Itaborahy L, Lima I, Colucci I, Soares L, Mariano P, Grito T. Fighting poverty among LGBTQI+ persons from Brazil: socioeconomic inclusion and the experience of Micro Rainbow International Foundation. HPHR. 2023;72. https://www.doi.org/10.54111/0001/TTT5</p> <p>Malta, M., da Silva, A.B., da Silva, C.M.F. et al. Addressing discrimination and violence against Lesbian, Gay, Bisexual, Transgender, and Queer (LGBTQ) persons from Brazil: a mobile health intervention. BMC Public Health 23, 2069 (2023). https://doi.org/10.1186/s12889-023-16857-4</p>

6.3. Other publications	<p>Baptista Silva A, Malta M, da Silva CMFP, Kalume CC, Filha IGA, LeGrand S, Whetten K. The Dandarah App: An mHealth Platform to Tackle Violence and Discrimination of Sexual and Gender Minority Persons Living in Brazil. Int J Environ Res Public Health. 2022 Dec 24;20(1):280. doi: 10.3390/ijerph20010280. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9819566/</p> <p>Malta M, Legrand S, Baptista da Silva A, Seixas M, Benevides B, Furtado Da Silva C. Rainbow resistance: development of a mobile app to address violence against LGBTQIA+ people in Brazil using a community based participatory research approach. HPHR. 2021;42. DOI: 10.54111/0001/PP2 https://hphr.org/42-article-malta/</p>
6.4. Other forms of communication, including conferences	<p>Reuters: https://www.reuters.com/article/idUSKBN1YM20V/</p> <p>https://nowtoronto.com/lifestyle/dandarah-app-brazilian-trans-women/</p> <p>Brazilian Ministry of Health: https://portal.fiocruz.br/noticia/aplicativo-dandarah-vai-mapear-zonas-de-risco-para-populacao-lgbt</p>
6.5 Other Evidence	<p>App on Google Play ("Dandarah - RISE"): https://play.google.com/store/apps/details?id=resistenciaarcoiris.org.pwa&hl=pt_BR</p> <p>App on Apple Store ("Dandarah"): https://apps.apple.com/ca/app/dandarah/id1490551406</p>
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