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## Early-stage innovation report

# Social Innovation in Health: research, public policy and agency capacity in the Colombian Zika Kids programme

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## INTRODUCTION

The Zika virus (ZIKV) epidemic in Colombia (October 2015–July 2016) affected more than 18 000 pregnant women.<sup>1</sup> As the epidemic advanced, evidence of the devastating consequences of congenital ZIKV infection was revealed, including microcephaly and other central nervous system birth defects. These health consequences posed significant public health challenges to the country, as highly vulnerable groups, such as mothers and young infants, experienced the greatest burden.

The ZIKV emergency posed significant public health challenges as there was a lack of knowledge about the natural history of this new disease. Specialised medical care procedures were not defined in the Colombian healthcare system, and approaching serious social and emotional implications for the primary caregivers was not easily addressed.<sup>2</sup> This was especially complex for economically disadvantaged mothers and families.<sup>3</sup>

In response to the enormous complexities arising from the ZIKV epidemic in Colombia, the National Institute of Health (NIH) created the Zika Kids programme to comprehensively address the clinical, social and health research impacts of congenital ZIKV infection in infants. In 2019, this programme was recognised by the Social Innovation in Health Initiative (SIHI) in the Latin America and the Caribbean region (LAC HUB) (the SIHI LAC HUB is formed by Pan-American Health Organization (PAHO) and the Centro Internacional de Entrenamiento e Investigaciones Médicas (CIDEIM) and the Universidad Icesi), for its innovative

## WHAT ARE THE NEW FINDINGS?

- ⇒ This social innovation demonstrates how a research oriented programme can generate evidence regarding a new disease such as congenital Zika virus infection, while simultaneously offering quality healthcare to a vulnerable population and providing data that could be applied in the design of public health policies.
- ⇒ The case study provides evidence on how a connection between social innovation, research, public policy generation, and quality and access to health can be established.
- ⇒ The innovation shows how the commitment of the innovative team and the creation of strong bonds between team members and the community can lead to improving the children's quality of life and to strengthening agency capacity in the mothers.

## HOW MIGHT IT IMPACT ON HEALTHCARE IN THE FUTURE?

- ⇒ Results from this research-based social innovation were integrated into public policies, which ultimately guarantee that the initiative will have a continuous impact on the population affected by congenital Zika virus infection.
- ⇒ Capacity was built in the health system, which can be useful for dealing with health emergencies in the future, in terms of replicating the approaches, mechanisms and stakeholder networks developed in the Zika virus emergency.
- ⇒ The results presented in this case study can prompt further analysis on the possible impact of social innovations on healthcare quality and public policies, which may be helpful to combat future health emergencies.

contribution to improving access and quality of healthcare for vulnerable populations.

A Social Innovation in Health (SIH) can be defined as: ‘a novel solution (process, product, practice, market mechanism) developed in response to a priority health need within a geographical context and implemented by different cross-sectoral organisations. [Such solutions have] enabled health-care delivery to be more inclusive, affordable and effective.’<sup>4</sup> The most relevant features of a SIH are: (1) participation based on the idea that communities and individuals are ‘[...] competent interpreters of their lives and essential contributors in solving the challenges to access quality health services’;<sup>5</sup> (2) the development of a creative solution to face health challenges; (3) the empowerment through the shifting of power relations; (4) the involvement of a more diverse range of actors beyond traditionally considered in public health;<sup>6–8</sup> and (5) changes in the social and institutional system produced as a result of the social innovation.<sup>9</sup>

The Zika Kids programme can be considered as a SIH in health service delivery, based on the comprehensive approach of social and health needs of patients and their families, linking the clinical, social and health management dimensions. Its main innovative component is the connection between research, public policy and access to quality healthcare. Its central SIH attributes are: (1) the participatory approach through the involvement of the children’s families as essential contributors in solving health challenges; (2) the cross-sectorial and multidisciplinary approach, involving different health system actors (researchers, health providers and various paediatric specialists), policy-makers and beneficiaries (patients and families); (3) changes were produced in the social system with the creation of the two foundations led by the children’s mothers, and, in the escalation of public health policies which allowed the improvement of access and quality of healthcare for children with congenital ZIKV exposure across the country.

The objective of this case study is to show how research-based social innovations can contribute to promoting access to quality healthcare, enabling a resilience process and generating public health policies to improve the health and well-being of a population affected by a complex disease. The aim of this analysis is to illustrate how this type of successful and creative solution constructed to face health challenges can be replicated; and also, how it contributed to broaden the understanding of the SIH concept, in this specific case, in its relationship with health research.

## METHODS

A qualitative research was undertaken using a case study methodology. The case was purposefully selected from the SIH database<sup>10</sup> managed by TDR (Research and Training in Tropical Diseases).<sup>11</sup> Innovations included in the database were identified through a public crowdsourcing methodology.<sup>12</sup> The case was selected based on the

following criteria: social innovation impact and scalability; implementation in an Andean region; and a focus on extending access and affordability to vulnerable populations.

Qualitative data were collected through observation, in-depth semistructured individual interviews, a semi-structured group interview and a review of all relevant documentation. Data were collected during two field visits to Barranquilla (November 2019 and February 2020), and interviews and observations were administered by principal investigator Dr Martha Milena Bautista-Gomez. Thirteen in-person interviews were conducted: nine individual interviews with members of the NIH, one individual interview with a strategic ally of the project and three group interviews with nine beneficiaries who were the parents of the children affected by the ZIKV. Each interview lasted 1 hour. Observation took place during visits to the homes of the beneficiaries and during participation in the multidisciplinary clinical follow-up appointments organised by the NIH, where photographic records were taken, and findings were then recorded in field diaries. The interviews and observations were used to collect information about the caregivers’ and children’s routines and the challenges they faced; on the relationships between the NIH team, the children and their families; on the work of the NIH team and its challenges and accomplishments; and on the bonds established between the families and, particularly, between the mothers of the children living with Zika. In addition to the primary data, document reports of the Zika virus epidemic in Colombia were analysed. This collection of data from different sources helped achieve the study’s objective.

Interviews were recorded, transcribed, and then organised and analysed using NVivo V.12 (QSR International). A thematic analysis using an inductive approach was applied with the goal of extracting lessons learnt from this social innovation. The categories of analysis were: social impact, access and quality in healthcare, and replicability and scalability.

## RESULTS

### Providing quality medical care during the development of health research

Within the Zika Kids programme, more than 60 children were evaluated during the first 2 years of their lives, and relevant information on their clinical profiles was retrieved and analysed. Simultaneously, at every visit, each child and family received a comprehensive evaluation by a transnational multidisciplinary team with unique experience in congenital ZIKV infection, which offered timely and updated interventions that improved children’s quality of life. This specialised team offered evidence-based care, and as a result of this process, important findings on the impact of the disease were identified, showing that many of the children

with microcephaly due to ZIKA virus infection presented other related conditions, such as epilepsy, swallowing difficulties and sleep disorders.

The findings resulting from the clinical evaluations of the children carried out by the visiting medical teams resulted in the development of a list of recommendations for the monitoring and care of paediatric patients with prenatal exposure to ZIKV published in December 2018 (NIH, 2018). The list defines the medical objectives, procedures, follow-up tasks and goals for each child's development stage, including (1) follow-up appointments with specialists in paediatrics and thorough anthropometric evaluations; (2) vaccination schedules; (3) feeding guidelines; and (4) intervention with physical, occupational and speech therapy. These recommendations allowed the specialised teams to offer evidence-based care.

Moreover, as the high quality of the clinical evaluations was a priority, the team not only developed recommendations for the care of children affected by the ZIKV but also used NIH resources to purchase specialised equipment that was needed for their treatment and that was not widely available in Colombia. This is explained in the following excerpt:

...The visiting medical teams operated with the NIH's own resources, with the latest technology for this type of follow-up, which implied the purchase of specialized equipment not available in the country, as is the case of the indirect retinoscopy examination using Retcam equipment, an examination that has been defined worldwide as the gold standard for evaluating eye damage caused by the Zika virus. (NIH, 2018:3)

As information from the clinical evaluations was organised and analysed, the team also shared findings in diverse scientific, academic and governmental settings as well as producing relevant publications in scientific journals, which contributed to understanding of this disease in terms of clinical manifestations, diagnostic tools and prognosis.<sup>13–23</sup>

Beyond the importance of these contributions to the scientific community, another valuable result from the research carried out by the NIH is that they could provide explanations for many of the children's behaviours and manifestations; because of this, it was possible to help each mother understand her child's condition and how to care for and control his or her symptoms:

The children cried all the time; they had to cry because they were hungry, but it was not easy for them to control their movements enough to take their bottle... you realize that feeding and sleeping are issues that we must intervene in to improve the quality of life of the child, of the family...

(Interview BI10, Innovative team, 19 November 2019)

#### The commitment of the innovator team and the mothers' agency capacity

One of the most relevant results from the Zika Kids programme is the strong bonds that formed between the team members, local community, families and mothers. The NIH team members—being a largely female team—were able to rapidly forge a connection with the families, especially with the mothers of the children, facilitating the medical process and ensuring continuous follow-up.

From the support network built during the multi-disciplinary clinical follow-up appointments, spontaneous and strong bonds consolidated between the mothers as they made connections, shared empathy and discussed their experiences. In this way, the visiting medical teams gradually became a familiar comfort, based not only on the medical care of their children, but also on emotional support, generating valuable listening moments for the mothers, as one of the mothers relates:

...for the visiting medical teams, aside from the fact that all the specialists attend, activities are done so that you feel like part of a family. We shared about how we were doing, how the children were doing, how their process was going on at home... We talked as if we were a family. She [the founder of the foundation] is always looking out for you, not only during the health brigade, she gets you in touch with Dr. Marcela over WhatsApp... (Interview BC09, Community, 20 November 2019)

In addition, the NIH began to educate the mothers about their health rights during these appointments, which motivated the beginning of social empowerment processes. In 2018, the mothers created two foundations, Miracles of God-Zika Kids in Neiva and Angels on Wheels in Barranquilla, to pursue common objectives. These foundations have been working to advocate for children's well-being and social inclusion. The challenges that the foundations want to address include psychosocial care and the development of productive projects for mothers as well as guaranteeing inclusive schooling for their children.

This process demonstrates how a negative situation has been redefined and transformed to enable the social empowerment of mothers to achieve better quality of life for their children. The mothers progressed from initial mourning to learning about the implications of their children's disability and then becoming advocates fighting to achieve better quality of life for their children, taking this on as a life project, as is showed in the following quote:

...They are little angels that did not harm our lives; they are little angels that have taught us a lot... in the

future I know that the Angels on Wheels Foundation is going to grow into a school; it is going to have its own school... a school that will not charge you for your studies...I know that it is going to happen with God's help; it is going to be a rehabilitation center... (Interview BC08, Mother-Community, 20 November 2019)

### Health policy and management to ensure access to healthcare for children with congenital ZIKV infection

The NIH has access to all cases of Zika-associated birth defects across the country. A list of these children, their health conditions and contacts was given to the National Family Wellbeing Institute, which pursued contact with these families to establish closer follow-up and help guarantee social support. The NIH team members raised the family and community needs with the local governments, where high-impact interventions such as mandating the delivery of complex health interventions were addressed:

...When a child is born with a catastrophic pathology, you need to know the path of what to do and when to do it. This allows you to optimize... the children's prognosis...it is more cost-effective to make the diagnosis, anticipate and act on prevention... (Interview BI10, Innovative team, 19 November 2019)

Research findings resulting from the Zika Kids programme were not solely used for academic purposes; they served as a reliable source of information to design healthcare policies and interventions, which could potentially improve healthcare delivery and access. During the development of the research process and upon gathering valuable information regarding disease manifestations and needed interventions, the NIH team considered it necessary to develop recommendations that could serve as guidelines for healthcare personnel across the country on how to address the needs of these children.

As a result, the team developed a document in which basic clinical interventions and recommendations were outlined. The NIH used its position as a generator of scientific evidence for public health policies to expand the scope of these recommendations and incorporate them into official policies. As such, the outlined recommendations were included in the 2019 official health benefits plan (Resolution 5857 of 2018).

The cross-sectoral stakeholder collaboration was a very important element of the process when implementing the recommendation list and achieving its scale-up to the public policy level. The NIH linked different organisations and sectors, managed resources, and established alliances with all kinds of actors within the health, academic, and scientific sectors. This allowed children with congenital ZIKV exposure to access the medical care needed according to the NIH recommendation list.

This inclusion allowed specific interventions to be covered by health insurance, preventing out-of-pocket medical spending. Additionally, a recommendation was given to the Ministry of Health to include all children exposed to ZIKV during pregnancy in the 'high-risk' paediatric group. This led to the inclusion of ZIKV-exposed children in this category under the national health promotion guidelines, facilitating specialised care (Resolution 3280 of 2018).

However, being officially regulated was not sufficient to ensure that the processes and procedures described were carried out in practice. It was necessary for the NIH to follow up on the compliance of the institutions in the provision of health services established by law and intervene in cases of non-compliance. The management implied cross-collaboration with the local health institutions and health provider institutions to streamline bureaucratic processes. Various institutions were able to appoint an officer to coordinate the care of children with congenital ZIKV exposure so that the NIH could send them the cases with the patients and treatment recommendations, transcribe medical orders, process authorisations, set up appointments and establish direct contact with the mothers.

## DISCUSSION

### Social and institutional change: the responsiveness of the health system and the mothers' leadership

Approaching a complex problem such as the ZIKV epidemic and its vast consequences required integrated and multilevel actions adapted to patients' needs within the social context using a holistic perspective. The Zika Kids programme worked at the community, institutional and political levels; furthermore, the programme promoted interinstitutional and multidisciplinary perspectives within the health sector, allowing for the improvement of healthcare access and delivery, reducing health system barriers and guaranteeing clinical attention.

On the one hand, the multidimensionality of the innovation and the integration of different actors improved the responsiveness of health providers to patients' needs. In other words, capacity was built in the health system, which can be useful for dealing with health emergencies in the future in terms of replicating the approaches, mechanisms and stakeholder network developed in the ZIKV emergency. This integration of a broad array of technical-scientific instruments, such as epidemiology, research and multidisciplinary clinical follow-up, allowed the NIH team to offer effective solutions to improve the health of children with congenital ZIKV infection and their families but also enabled the inclusion of a vulnerable population that faced effects of having a rare disease and made healthcare affordable by creating mechanisms that allowed access to quality healthcare.

On the other hand, support networks consolidated between the mothers, which would soon lead to the development of leadership skills that extend beyond the



realms of health. Through this process, these women have acquired important learning experiences in health administrative procedures, health rights, knowledge about the control and management of their children's condition and the development of a set of different initiatives to improve their children's quality of life. These initiatives range from the development of productive projects to the visualisation of a learning centre that will support all stages of their children's growth and development. This capacity building among the mothers has allowed them to develop their agency capacity in coping with their children's disability and facing other personal and familial life processes.

#### **Shifting power dynamics: the community's contributions and the commitment of healthcare providers**

One of the most interesting points about this social innovation concerns how its relationship with health research resulted in community participation in the entire research process, which shifted the usual power dynamics in health. This type of patient participation enables a better understanding of complex problems and offers innovative approaches to finding solutions. It is also intended to promote social transformation, community empowerment and knowledge sharing. Finally, it ensures the relevance and acceptability of research<sup>24</sup> and improves the responsiveness of healthcare systems to people's health needs.<sup>25</sup>

Another component of this social innovation that contributed to shifting power dynamics is the social awareness, empathy and commitment of the health practitioners, which had positive effects on the improvement of patients' quality of life. Incorporating these qualities into their work leads health practitioners to better understand their patients' feelings, opinions and experiences, which allows them to better assess their patients' needs and design and implement solutions accordingly; in turn, there are better results and a higher probability of improvement for patients.<sup>26</sup> In this case, the close interactions between researchers and participants and the fact that they were grounded in real-life facts and contextualised realities were enormously relevant in solving issues surrounding the disease.

As observed from this innovation, the research team involved patients, families, local leaders and government members with the goal of offering realistic solutions to difficulties that could only be identified through strong community interactions. These challenges mainly revolved around the children's health issues, but many could not be addressed with health-centred actions, instead benefiting from the support and commitment of other families and local leaders. This reflects the importance of taking a participatory approach, where comprehensive interventions are created around real-life difficulties.

#### **Political and social sustainability: scalability through public health policies and social empowerment**

One of the strengths of this innovation lies in its sustainability from a political and social point of view. Regarding political sustainability, the NIH was able to escalate solutions and integrate them into public policies. The greatest claim of this social innovation is its influence on public policies, which ultimately guarantees that the initiative will have a continuous impact on the population. Achieving this type of sustainability and scalability implies that access to healthcare and health interventions is protected not only for current but also for 'future' patients,<sup>27</sup> thus achieving the highest level of sustainability.

Second, the empowerment process ensured the social sustainability of this innovation because its impacts extend beyond health, creating agency capacity in mothers, who were able to redefine the process of mourning for their children's disability and turn this into something positive, where advocacy for their children's well-being is now the driving force of their lives. This capacity building ensures that the process of achieving the well-being of children with Zika will go beyond the NIH programme.

However, the main challenge of the innovation lies in its financial sustainability, since the ZIKV epidemic has ended, and therefore, the provision of resources is now much more limited. Therefore, from now on, obtaining financial resources will depend on the generation of new projects based on improving the quality of life of children living with Zika in their development and growth process with their disability.

#### **CONCLUSION**

The described innovation demonstrates how a research-oriented programme was able to not only generate evidence regarding a new disease such as congenital ZIKV infection but also simultaneously offer quality healthcare to a vulnerable population and organise data that could be applied in the design of public health policies, creating impactful changes at the health and social system levels. This type of innovation should prompt further analysis, as it may be resourceful to combat future health emergencies.

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**Ethics approval** The case study protocol was approved by the CIDEIM (Centro Internacional de Entrenamiento en Investigaciones Médicas) Ethics Committee for Research of Human Subjects. Participant consent forms were signed at every visit.

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