JOURNAL OF MARKET ACCESS & HEALTH POLICY
2023, VOL. 11, 2211868
https://doi.org/10.1080/20016689.2023.2211868

Routledge
Taylor & Francis Group

ORIGINAL RESEARCH ARTICLE

Quantitative revenue estimates and qualitative assessments of innovative fundraising sources for treating rare diseases in Colombia

Surrey M Walton [a], Wilson Mayorga[b], Angela Rodríguez Narváez[c], Maria Alejandra Chavez[d], Natalia Cortés Guesguán[c*], Luis Durango[e] and Ludy Alexandra Parada[e]

[a]Managing Partner, Second City Outcomes Research LLC, Oak Park, IL, USA; [b]Actuary Manager, Numeris, Bogota, Colombia; [c]Economist, Numeris, Bogota, Colombia; [d]Researcher, IQVIA, Bogota, Colombia; [e]Public Policy Team, Roche, Bogota, Colombia

ABSTRACT

Background: Like many developing countries, Colombia faces difficulties in financing health-care services as well as programs for health promotion and health education and there is evidence that its health-care system is underperforming.

Objective: To provide evidence-based estimates of potential funding levels and assess the strengths, weaknesses, and viability of innovative funding mechanisms with a focus on treating rare diseases in Colombia.

Methods: The strategy involved evidence-based projections of potential funding levels and a qualitative viability assessment using an expert panel.

Results: Crowdfunding, corporate donation, and social impact bonds (SIBs) were deemed to be the most viable of numerous potential strategies. Expected funding levels over 10 years for rare diseases in Colombia from crowdfunding, corporate donations, and SIBs were roughly $7,200, $23,000, and $12,400, respectively.

Conclusions: Based on the combination of projected funding potential along with expert consensus regarding viability and operability, crowdfunding, corporate donations, and SIBs, especially in combination, have the potential to substantially improve funding for vulnerable patient populations in Colombia.

ARTICLE HISTORY
Received 3 February 2023
Revised 1 May 2023
Accepted 5 May 2023

KEYWORDS
Innovative; fundraising; rare disease; Colombia

Introduction

Like many developing countries, Colombia faces difficulties in financing health-care services as well as programs for health promotion and health education and there is evidence that its health-care system is underperforming in producing health [1]. Meanwhile, vulnerable populations, patients in rural areas, as well as patients with rare diseases in Colombia face limited access to treatments and services leading to health disparities and sub-optimal health outcomes. Innovative funding mechanisms can play an integral role in Colombia to improve access to care, reduce disparities, and improve overall health [2,3]. As described in more detail below, we focus on three potential sources of funding: corporate donations, crowdfunding, and social impact bonds (SIBs). While corporate donations and crowdfunding are more traditional sources of funding, SIBs are a relatively new financing mechanism where private investors put up funds and receive a rate of return that depends on the successful use of the funds, usually by a government entity. SIBs were first described and actively used in 2010 as part of a plan to implement a prisoner rehabilitation project in the UK [4,5]. SIBs were first used as part of a health-related financing plan in the US in 2013, where they were employed to fund an intervention aimed at reducing chronic asthma in low-income children residing in Fresno California and have grown since then. Corporate donations and crowdfunding have also been growing as funding mechanisms for health services [6–8].

To help inform potential strategies for financing health programs in developing countries, and in particular for funding rare diseases in Colombia, this study highlights findings from a recent effort led by members of Numeris and IQVIA to assess innovative funding mechanisms. The project involved a qualitative viability assessment exercise using an expert panel and generating evidence-based projections of potential funding levels. The overarching goal was to provide specific guidance for creating innovative funding mechanisms to promote impactful health programs for patients with

CONTACT Surrey M Walton Surrey.max.walton@secondcityoutcomesresearch.com Managing Partner, Second City Outcomes Research LLC
*Changed to Data Analytics, Transunion (Cifin)

rare diseases in Colombia, which, in turn, can also guide efforts to assist other vulnerable populations in Colombia and in other developing countries. The specific purpose for this manuscript is to describe the qualitative assessment of viability, the funding projections, and the identified specific strengths and weaknesses for the top funding strategies.

Materials and methods

Expert panel projections of viability

To augment the funding projections, five economists were selected with specific training and expertise related to funding mechanisms (see Table 1) to participate in a qualitative exercise to rank the operability and viability of potential funding mechanisms for Colombia that included a recreational cannabis tax, SIBs, a carbon tax, corporate donations, benefit concerts, crowdfunding, air miles, and a medicinal cannabis tax.

Each of the experts was tasked with ranking each of the alternatives according to ease of operation and viability to finance rare diseases in Colombia. The results of the indicated preferences were grouped using the social choice methodology known as the Borda count which is an index based on the relative ranking. For this specific exercise, there were eight potential categories to rank and hence the number 1 ranking in terms of operability and viability would receive seven points, the second rank six points, and so on based on the rankings of each of the participants.

Funding projections

Based on the strategies of evaluation and available information regarding similar funding efforts in similar countries, consensus-based projections of net funding levels were constructed for 10-year periods. These estimates were formed using Colombian pesos which have been converted to US dollars using the average exchange rate in 2022 (4257.6765 pesos per dollar) [9]. For crowdfunding, the strategy involved sampling representative campaigns in Colombia and forming projected net revenue based on the average donation seen, the number of potential donors, and subtracting the costs of the campaign as seen in the following equation:

$$VRi = (PDi*Di) - Ci$$

where VR*i* is the overall net revenue, PD*i* is the average donation in year *i*, D*i* is the projected total number of donors in year *i*, and C*i* is the cost associated with the campaign in year *i*. For the consensus base case inputs, a sampling was conducted from the 'Vaki' platform in Colombia, wherein a beneficiary can be an individual or a legal entity that subscribes and publishes the collection campaign of their choice in exchange for the payment of a commission for the donation received [10]. Funders can access the platform to donate to the campaign of their choice. To form the estimate, a total of 40 campaigns were included, of which more than half were designated for assisting with funding treatments and/or services for patients with rare, genetic, and/or high cost diseases. The other funds were included based on having substantial numbers of donors along with relatively large publicity and promotion to reflect the potential for a broad effort via national health entities. From these programs, the average donation was found to be $142.233 Colombian pesos (roughly 3 cents) with a sample standard deviation of $138.328 and the number of donors was found to be 0.051% of the total population of Colombia in 2021, amounted to approximately 20,000 donors. Based on these, population growth estimates over a 10-year period based on the official Colombian population count known as DANE and a constant rate of donors per population were incorporated to project funding levels [11]. Costs of the funding were estimated to be 13% of the gross collection which includes the 'Vaki' platform commission, financial costs, a standard 4×1000 tax, and marketing costs, based on public information regarding the costs of large-scale campaigns in the sample. Total projections use currency with a base year of 2022.

Projections for potential funds from corporate donation were formulated based on likely funding levels per

Table 1. Expert panel for ranking funding sources.

Type of expertise	Primary degree	Key experience
Crowdfunding	Masters in Actuary and Quantitative Finances	UIAF, Banco de la Republica, RAPPI
Health and Narcotics	Masters in Public Policy	Head of Planning and Sectoral Studies of the Ministry of Health
Health and Public Politics	Masters Degree in Industrial Economics	Advisor to the DNP and Ministry of Health
Economist	PhD in Economics	Professor at the Jorge Tadeo University
Tax Expert	Masters in Economics	Advisor to the District Secretary of Finance and DIAN

donor multiplied by the number of potential donors with separate amounts for large- (greater than 50 employees) versus small- and medium-sized corporations. The percent of donations given to health-care programs for rare diseases was also incorporated as described by the following equation:

$$VRi = ((PDiLC * DiLC) + (PDiSMC * DiSMC)) * \%EH$$

where VRi is the value collected in year *i*, PD*i*LC is the average donation in year *i* from large companies, PD*i*SMC is the average donation in year *i* from small and medium companies, D*i*LC is the total number of donors made up by large companies, D*i*SMC is the number of donors made up by small- and medium-sized companies, and %EH*i* is the expected percent allocated to health for patients with rare diseases in year *i*.

Average donations were projected based on the typical proportion of profits allocated to donations which was 2.946%, multiplied by average profits seen in large companies and separately in small- and medium-sized companies. Projections of the number of donors were based on the information available from the Superintendence of Societies itself encompassing 1110 large companies and 38,371 small- and medium-sized companies and proportion of those that belong to the Association of Family Foundations which specifically expresses intention of corporate social responsibility and with a cause of interest within the 'Sustainable Development Goal Number 3 of the 2030 Agenda', 'Health and Well Being' [12]. For large companies, this was a total of 41 in 2021 and for small- and medium-sized companies this was 1417. Finally, the Associacion Nacional De Industriales (ANDI) Social Architecture survey found that companies tend to allocate 25% of their total donations to health. From those levels, to get a potential for rare diseases, the consensus was to use 60% of health donations. In addition, to project across a 10-year period, a growth rate of 1.64% for large corporations and 0.3724% for small- and medium-sized corporations was incorporated based on results in the Charities Aid Fundation (CAF) World Giving Index for Colombia relative to the US and available growth rates in donations in the US for large and small and medium companies.

Projections for funding levels from SIBs relied on findings from the literature review. To begin, existing SIBs have had durations of 2–7 years. Hence, the projections were based on two 5-year bonds. Further, the estimates centered on information available in a recent wide reaching survey article regarding SIBs for noncommunicable diseases that included information on invested capital, expected reimbursement, and returns to capital [4]. To project potential funding

for health programs related to rare diseases in Colombia, the international experience deemed to be most consistent was selected based on health spending levels. From the available selection of existing SIBs, the country with the most similar health expenditures was Israel (74.8 billion pesos for Colombia in 2019 versus 74.8 billion for Israel). The specific level of capital invested in Israel was equivalent to 0.032354% of its health spending, which was applied to project for Colombia for the first 5-year period and then a 3% long-term inflation rate was applied to estimate the second 5-year period.

Results

Expert panel ranking results

Among numerous potential funding mechanisms including various taxation schemes, crowdfunding was ranked as the most viable and operable with 41 points followed by business donations at 36 and SIBs at 26.

Funding projection results

Table 2 summarizes the projected potential funding amounts for rare diseases and for crowdfunding, corporate donations, and SIBs over two 5-year periods. Funding levels over 10 years for rare diseases in Colombia from crowdfunding, corporate donations, and SIBs were roughly $7,200, $23,000, and $12,400, respectively.

Specific strengths and weaknesses

The specific strengths of crowdfunding in Colombia, which can be accomplished with the existing platforms known as VAKI and YOApoyo, include the ability to select specific donation categories such as health. Further, there are no intermediaries, large numbers of donors can invest in the same project, transaction costs and financial risk are relatively low, and users can monitor their donation. In addition, the process is simple, it serves to improve social engagement with causes, and it can involve small or large levels of individual donation.

Table 2. Funding projections in 5-year periods.

Years	Crowdfunding	Corporate donations	Social impact bonds
1–5	$3,255.77	$10,455.94	$5,760.89
6–10	$3,942.53	$12,846.44	$6,678.53

Note: Currency is US dollars in 2022.

Weaknesses of crowdfunding include informational asymmetry between the creators and the funders of projects that can lead to herd mentality as well as the potential for increased social inequality via competition across particular projects. In addition, there is a limited regulatory framework in Colombia focused around efforts by legal entities designed to obtain economic profitability from business, agricultural, industrial, commercial activities or services, which, in turn, leaves open the potential for fraud [2].

Strengths of corporate donations include a natural synergy between healthy societies and healthy corporate environments in which to operate. Further, government incentives, including tax exemptions for corporate donations, often feed into these synergies. In addition, corporate donations can extend and accentuate loyalty and permanence of donations given the value of image to corporations and the engagement of charities with donating corporations [13].

Disadvantages are that legal structures around corporations can be fraught with ethical problems. Further, individual behaviors of executives and specific profit incentives for companies and shareholders may hinder the development of socially motivated donations. For rare diseases in particular, generating donations may require special incentives from the government.

Strengths of SIBs are that they are more viable than tax rate increases as they are further removed from political lobbyists. In addition, using SIBs, because the returns are based on measures of success of the underlying program, transfers the risk of success of the related program from the government to the funders. Moreover, they lend themselves to financing preventive services that can save future governmental expenditures [4,14].

Weaknesses are the possibility of shifting basic governmental services to private entities that proceed to fail in the terms of delivery. In addition, they remain a relatively new mechanism with complexity in design and few precedents for financing in Colombia beyond employment programs. Further, they can have substantial costs associated with coordination of the entities involved in financing along with tracking and establishing meaningful measures of success to trigger the rates of return to funds [4]. Relatively, they require relationships of trust between public, private, and not for profit entities, and without legal requirements future government administrators may fail to make payments. Also, and in particular to health programs, many outcomes can be related to multiple factors that are not related to the primary program being funded such that programs may look successful when really there were not, and at the same time there is a risk related to scope where payments and therefore incentives are related to metrics that are not sufficient to generate actual improvements in health.

Discussion

The projections are based on consensus and evidence driven; however, wide bounds should be considered around the mean estimates described here before there is more real-world experience in the specific area of rare diseases.

In terms of implanting a specific funding strategy around rare diseases, previous efforts, particularly with respect to SIBs, strongly suggest that evidence-based programs aimed at specific patient populations have the highest chance at success [4]. Other factors include support of professional organizations, strong stakeholder support, and effective and easy to understand communication of the program goals [15]. As described above, there are several other vulnerable patient populations that could benefit from innovative funding in Colombia and in other developing countries [3]. The evidence presented here suggests that meaningful gains could be made particularly with a concerted effort to establish these three strategies deemed most viable: crowdfunding, corporate donations, and SIBs. Based on our estimates, corporate donations are expected to provide the largest gain; however, each of the mechanisms can contribute to assist patients with access to care. Further, there is existing infrastructure and experience in Colombia to build upon. Every effort should be made to ensure against potential fraud and to establish and maintain trust for the donors that the underlying programs are legitimate and have strong chances for success.

Conclusion

Based on the combination of projected funding potential along with expert consensus regarding viability and operability, crowdfunding, corporate donations, and SIBs, especially in combination, have the potential to substantially improve funding for vulnerable patient populations in Colombia. Efforts should be made to create and couple evidence-based programs with funding strategies to best promote health and reduce disparities in Colombia as well as for other developing countries.

Acknowledgments

Funding for the study was provided by Roche. Employees of Numeris and IQVIA participated in the research efforts.

Disclosure statement

No potential conflict of interest was reported by the authors.

Funding

The work was supported by the Roche.

ORCID

Surrey M Walton http://orcid.org/0000-0001-7458-6460

References

[1] Mor N. Lessons for developing countries from outlier country health systems. Front Public Health. 2022;10:870210.
[2] Lubloy A. Medical crowdfunding in a healthcare system with universal coverage: an exploratory study. BMC Public Health. 2020;20(1):1672.
[3] Bhaat J, Bathija P. Ensuring access to quality health care in vulnerable communities. Acad Med. 2018;93(9):1271–1275.
[4] Hulse ESG, Atun R, McPake B, et al. Use of social impact bonds in financing health systems responses to non-communicable diseases: scoping review. BMJ Glob Health. 2021;6(3):e004127.
[5] Social Finance. Social impact bonds: rethinking finance for social outcomes. 2009. Accessed 2023 May 8. https://www.socialfinance.org.uk/insights/social-impact-bonds-rethinking-finance-for-social-outcomes.
[6] Dragojlovic N, Lynd LD. Crowdfunding drug development: the state of play in oncology and rare diseases. Drug Discov Today. 2014;19(11):1775–1780.
[7] Iqbal S, Collins DC. Crowdfunding for anticancer therapies: an analysis of non-US GoFundMe pages. Ir J Med Sci. 2021;190(4):1355–1361.
[8] Otero PC. A new option for funding health projects. Arch Argent Pediatr. 2015;113(2):154–157.
[9] UK ER US Dollar to Colombian Peso Spot Exchange Rates for 2022. https://www.exchangerates.org.uk/USD-COP-spot-exchange-rates-history-2022.html. Published 2023. Accessed 2/1/2023.
[10] VAKI. VAKI Collective Funding Web Page. https://vaki.co/es/. Accessed 4/27/2023, 2023.
[11] DANE GC. https://www.dane.gov.co/. Published 2023. Accessed January 26, 2023.
[12] United NationsUSustainable Development Goals. https://unstats.un.org/sdgs. Published 2023. Accessed January 26, 2023.
[13] Tesler LE, Malone RE. Corporate philanthropy, lobbying, and public health policy. Am J Public Health. 2008;98(12):2123–2133.
[14] Belinsky M, Eddy M, Lohmann J, et al. The application of social impact bonds to universal health-care initiatives in South-East Asia. WHO South East Asia J Public Health. 2014;3(3):219–225.
[15] Koole MAC, Kauw D, Winter MM, et al. A successful crowdfunding project for eHealth research on grown-up congenital heart disease patients. Int J Cardiol. 2018;273:96–99.