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Title	Medical Crowdfunding in India: The Need for a Strong Legal Enforcement System
Type	Article
URL	https://clock.uclan.ac.uk/53185/
DOI	https://doi.org/10.4103/ijph.ijph_1081_23
Date	2024
Citation	Bhat, Lekha D., Panneer, Sigamani, Bhagyalakshmi, R., Kantamaneni, Komali, Nayar, Kesavan Rajasekharan and Rice, Louis (2024) Medical Crowdfunding in India: The Need for a Strong Legal Enforcement System. <i>Indian Journal of Public Health</i> , 68 (3). pp. 441-443. ISSN 0019-557X
Creators	Bhat, Lekha D., Panneer, Sigamani, Bhagyalakshmi, R., Kantamaneni, Komali, Nayar, Kesavan Rajasekharan and Rice, Louis

It is advisable to refer to the publisher's version if you intend to cite from the work.
https://doi.org/10.4103/ijph.ijph_1081_23

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Medical Crowdfunding in India: The Need for a Strong Legal Enforcement System

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Summary

In India, poor health insurance coverage and high out-of-pocket expenditure especially for chronic and rare genetic/life-threatening diseases is a reality. People who use medical crowdfunding as an option to meet medical expenditures and the sudden growth of new fundraising platforms are significant developments in healthcare. The digital platforms in fundraising and the multitude of transactions they perform are increasing in the country and have a significant impact on the health sector and the rights of the patients which points toward the need for more effective regulation. In the absence of sector-specific legislation and government guidelines, the paper summarizes the growth of medical crowdfunding in India, identifies the challenges, and reiterates the need for effective legal enforcement systems.

Key words: India, legal enforcement system, medical care, medical crowdfunding, regulation

Quality medical care for all is an integral part of a robust public health system and India in its Constitution declares improvement of public health and public assistance during sickness or disability as state responsibility. Despite these constitutional mechanisms, the health insurance sector covers only 40% of the population and out-of-pocket expenses account for nearly 63% of health-care expenditures.^[1] Access to appropriate and affordable care especially for life-threatening/genetic diseases, and accidents are a serious challenge for the Indian health-care system. The increase in people who use medical crowdfunding as an option to meet medical expenditures and the sudden growth of new fundraising platforms are significant developments in this context. The expansion of medical crowdfunding is fuelled by gaps in the social safety net, rising health-care costs, and inadequate access to health-care coverage.^[2] The rise of digital platforms, particularly for raising the finances required for medical treatments in countries where out-of-pocket expenditure is too high is a new public health development.^[3]

Medical crowdfunding represents an important way in which people respond to the gaps in national health payment systems

wherein online platforms raise money for those who have medical costs.^[4] The usage of crowdfunding websites for medical expenses is increasing by 25% annually.^[2,4] The lower the national insurance coverage in a country, the greater the number of medical crowdfunding projects emerge.^[5]

This paper focused on articles to get an understanding of the concept of medical crowdfunding in the Indian context, followed by newspaper reports, and other reports about medical crowdfunding issues in India and suggest pragmatic legal enforcement mechanisms.

In India, medical crowdfunding platforms such as Ketto, Milaap, and Impact Guru are very popular and the use of medical crowdfunding has increased in the country. The use

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Submitted: 22-Aug-2023

Revised: 09-Mar-2024

Accepted: 30-Mar-2024

Published: 24-Sep-2024

How to cite this article: Bhat LD, Panneer S, Bhagyalakshmi R, Kantamaneni K, Nayar KR, Rice L. Medical crowdfunding in India: The need for a strong legal enforcement system. *Indian J Public Health* 2024;68:441-3.

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Website:
<https://journals.lww.com/IJPH>

DOI:
10.4103/ijph.ijph_1081_23

of medical crowdfunding is expected to continue to increase, it is growing at a rate of 25% per year.^[6]

Medical crowdfunding is a process wherein digital technology is used to connect people who wish to give and receive financial aid for medical care. It involves campaigners/fundraisers (people who create a fundraising request; might be patients or their representatives (family/friends/acquaintances). People who wish to contribute (donors) can visit the sites, go through the video of the fundraiser or the write-up provided, and decide to donate. The platforms (intermediaries) promote campaigns for people who require medical care through targeted advertising on social media.

In India, medical crowdfunding platforms have started gaining momentum since the launch of Milaap (2010), Ketto (2012), and Impact Guru (2014). In the Indian context, the legal definition of crowdfunding in the Securities and Exchange Board of India (SEBI) Consultation Paper on Crowdfunding is “solicitation of funds from multiple investors through a web-based platform or social networking sites for a specific project, business venture, or social cause.”^[7] This solicitation of funds is for philanthropic medical care support.

The process of bringing together the donors and beneficiaries is initiated and managed by the intermediaries, i.e., crowd platforms. This is done by verifying their medical needs and treatment, verification of the campaigner’s identity, and realistic fundraising goals, and developing a personal appeal to the donor by narrating their medical condition. Most of the platforms state on their website that there is no platform fee charged, whereas some reports mention that 10%–15% of the funds raised is deducted as commission.^[4,6] Table 1 gives an overview of the prominent medical crowdfunding platforms in India.

The medical crowdfunding platforms involving multiple stakeholders and beneficiaries need regulatory interventions in light of possible contraventions. Contributing factors such as low entry barriers to creating and donating to campaigns, the spatial and temporal separation between campaign creators, donors, and beneficiaries coupled with the anonymity involved contribute to this increased risk of misusing the platforms.^[8]

Indian legal and regulatory regime on medical crowdfunding is in its nascent stage. There is no independent legislation or regulator to monitor these donation-based crowdfunding platforms; nevertheless, these transactions attract laws such as the Income Tax Act, of 1961, Foreign Contribution Regulation Act, of 2010, Information Technology Act, of 2000, and the Information Technology (Intermediary Guidelines and Digital Media Ethics Code) Rules, 2021. The taxation regime of crowdfunding depends on the institutions or organizations involved in the process. The exemptions provided under the taxation laws are by donations made to charitable and nongovernmental organizations (NGOs). However, individual fundraisers who do not fall into the exemption category have to pay the taxes and the donors should be aware that these donations will not entirely be used for the intended cause since taxation will apply.^[9] In a similar context, a certificate mandated under the Foreign Contribution Regulation Act as a prerequisite for raising donations from foreign citizens inherently places limitations on fundraisers on a crowdfunding platform and mandatory compliances are warranted. The Information Technology Act provides for exemption of liability for intermediaries and states that an intermediary shall not be liable for any third-party information, data, or communication link made available or hosted by them (Section 79[1] of the Information Technology Act, 2000).

Studies from other countries show that there are a significant number of issues, for example, fundraisers fake/exaggerating their illness, fake/exaggerate another person’s illness, impersonation, or misapplication of funds.^[10] In India, instances of fake fundraising and the amount not reaching the mentioned patient in need of medical help have been widely reported. In some instances, medical documents of the patient are misused to raise funds.^[9]

Crowdfunding platforms contend that they exercise due diligence measures before hosting the campaigns. Any cases of misleading or fraudulent campaigns can be reported to the website and if the investigation of the cases is proven, donors can be informed and refunded. However, the refund policy indicates that a refund is only possible if funds are not transferred to the recipient (Milaap website-terms, and

Table 1: Major medical crowdfunding platforms in India*

Company	Year of establishment	Amount raised (INR)	Main diseases covered	Fee and user/donor numbers
Ketto	2012	18.50 billion	Heart surgery, kidney transplantation, NICU care, cancer treatment, bone marrow transplant	Zero percent platform fee. 5.5 million donors and more than 0.2 million beneficiaries
Milaap	2010	18.60 billion	Cancer, accidents, rare genetic diseases, neurological issues, and other life-threatening conditions	Zero percent platform fee. 7.8 million donors and more than 0.65 million beneficiaries
Impact Guru	2014	15 billion	Kidney transplant, cancer, bone marrow, heart transplant, COVID-19 support	Depending on fundraising needs charge a certain amount as a fee or sometimes zero percent platform fee. 2 million donors and 0.2 million beneficiaries
Donate Kart	2016	1.5 billion	Work with NGOs to support the medical requirements of their beneficiaries	Zero percent platform fee. 0.1 million donors and 1000 NGOs as fundraisers

*Source - Official Websites of Ketto, Milaap, Impact Guru, and Donate Kart accessed on April 8, 2023. NGOs: Nongovernmental organizations, NICU: Neonatal intensive care unit, INR: International normalized ratio

conditions accessed on March 12, 2023). Although in many cases the intermediaries declare that the received amount has been fully transferred to the beneficiaries, there are cases contrary to this claim.^[9,10] Most of the platforms mentioned on their website claim of zero percent platform fee; however, these platforms are registered as private companies (not as NGOs) with a large staff size which includes IT professionals, videographers, creative writers, web designers, and media professionals. It is somewhat unclear how these companies meet the financial component of administrative, workforce, and technical support requirements. Most platforms in this category are for-profit entities, raising money from fees or “tips” on donations given to campaigns.

Despite the assurances of verifying the beneficiary credentials, the terms and conditions indicated on the websites of donation-based crowdfunding platforms clarify that they cannot be held liable for the correctness of the information on the platform. Similarly, the platforms assume no responsibility for the outcome of the project or verify whether the funds are utilized for the same purpose.

The multiplicity of stakeholders involved and the increasing volume of contributions in the crowdfunding model raise significant concerns and challenges. According to the SEBI’s current guidelines, donation-based crowdfunding, wherein the fundraisers directly seek donations from the donors, and reward-based crowdfunding is legal. However, there is currently no independent legislation or sector-specific regulator to monitor the medical crowdfunding platforms.

There is a need to develop a legal mechanism to ensure that fraudulent campaigns are not promoted and removed, the amount collected is received by the patient according to the terms and conditions known to the donor, and the money donated will be spent on medical treatment as claimed in the campaign. There is a need to develop regulatory mechanisms without raising unnecessary barriers to the utilization of these platforms.

The effective legal intervention and enforcement measures for medical crowdfunding platforms can be effectuated through the establishment of an independent regulatory authority such as SEBI or RBI or by devolving additional powers of this regime to the existing regulators. Similarly, there has to be an incorporation of statutory provisions for compliance with medical crowdfunding in the existing legislation. There also has to be a redefining of due diligence and disclosure transparency since the fixation of liability for the platforms

being a muddled ground requires successive amendments in the rules framed under the IT Act, 2000. Added to this, the regulatory oversight by the independent regulator can mitigate the chances of entities deriving undue advantage through fake campaigns.

As an increasing number of people across India are turning to online medical crowdfunding platforms to meet their health-care requirements, it is essential to develop legislation or control mechanisms. Rather than considering crowdfunding as a social media fad or a purely benevolent charity act, researchers and the government need to recognize it as a complex innovation that is reshaping health systems that require stronger regulatory mechanisms.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

REFERENCES

1. Sriram S, Khan MM. Effect of health insurance program for the poor on out-of-pocket inpatient care cost in India: Evidence from a nationally representative cross-sectional survey. *BMC Health Serv Res* 2020;20:839.
2. Berliner LS, Kenworthy NJ. Producing a worthy illness: Personal crowdfunding amidst financial crisis. *Soc Sci Med* 2017;187:233-42.
3. Rice L, Sara R. Updating the determinants of health model in the information age. *Health Promot Int* 2019;34:1241-9.
4. Snyder J, Zenone M, Crooks V, Schuurman N. What medical crowdfunding campaigns can tell us about local health system gaps and deficiencies: Exploratory analysis of British Columbia, Canada. *J Med Internet Res* 2020;22:e16982.
5. Bassani G, Marinelli N, Vismara S. Crowdfunding in healthcare. *J Technol Transf* 2018;44:1290-310.
6. Christopher Updated; 2022. Available from: <https://www.ketto.org/blog/success-of-from-u-2-them-fundraiser-on-ketto>. [Last accessed on 2022 Apr 08].
7. SEBI Consultation Paper on Crowdfunding in India, Securities Exchange Board of India. Available from: https://www.sebi.gov.in/reports/reports/jun-2014/consultation-paper-on-crowdfunding-in-india_27102.html. [Last accessed on 2023 Apr 25, Last updated on 2014 Jun 17].
8. Siering M, Koch J, Deokar A. Detecting fraudulent behavior on crowdfunding platforms: The role of linguistic and content-based cues in static and dynamic contexts. *J Manage Info Sys* 2016;33:421-55.
9. The Hindu Business Line, Raising Money Efficiently via Crowdfunding Platforms. Available from: <https://www.thehindubusinessline.com/opinion/raising-money-efficiently-via-crowdfunding-platforms/article37066949.ece>. [Last accessed on 2023 Apr 23, Last updated on 2021 Oct 19].
10. Zenone M, Snyder J. Fraud in medical crowdfunding: A typology of publicized cases and policy recommendations. *Policy Internet* 2018;11:188.