

PUBLIC ENGAGEMENT AND CROWDFUNDING IN HEALTH RESEARCH

A Practical Guide



PUBLIC ENGAGEMENT AND CROWDFUNDING IN HEALTH RESEARCH

A Practical Guide



Public engagement and crowdfunding in health research: a practical guide

ISBN 978-92-4-003908-7 (electronic version)

ISBN 978-92-4-003909-4 (print version)

© World Health Organization on behalf of the Special Programme for Research and Training in Tropical Diseases, 2021

Some rights reserved. This work is available under the Creative Commons Attribution-NonCommercial-ShareAlike 3.0 IGO licence (CC BY-NC-SA 3.0 IGO; <https://creativecommons.org/licenses/by-nc-sa/3.0/igo>).

Under the terms of this licence, you may copy, redistribute and adapt the work for non-commercial purposes, provided the work is appropriately cited, as indicated below. In any use of this work, there should be no suggestion that WHO, including TDR, endorses any specific organization, products or services. The use of the WHO and TDR logos is not permitted. If you adapt the work, then you must license your work under the same or equivalent Creative Commons licence. If you create a translation of this work, you should add the following disclaimer along with the suggested citation: “This translation was not created by the World Health Organization (WHO) or by the Special Programme for Research and Training in Tropical Diseases (TDR). WHO, including TDR is not responsible for the content or accuracy of this translation. The original English edition shall be the binding and authentic edition”.

Any mediation relating to disputes arising under the licence shall be conducted in accordance with the mediation rules of the World Intellectual Property Organization.

Suggested citation. Public engagement and crowdfunding in health research: a practical guide. Geneva: World Health Organization; 2021. Licence: [CC BY-NC-SA 3.0 IGO](https://creativecommons.org/licenses/by-nc-sa/3.0/igo).

Cataloguing-in-Publication (CIP) data. CIP data are available at <http://apps.who.int/iris>.

Sales, rights and licensing. To purchase WHO publications, see <http://apps.who.int/bookorders>. To submit requests for commercial use and queries on rights and licensing, see <http://www.who.int/copyright>.

Third-party materials. If you wish to reuse material from this work that is attributed to a third party, such as tables, figures or images, it is your responsibility to determine whether permission is needed for that reuse and to obtain permission from the copyright holder. The risk of claims resulting from infringement of any third-party-owned component in the work rests solely with the user.

General disclaimers. The designations employed and the presentation of the material in this publication do not imply the expression of any opinion whatsoever on the part of WHO, including TDR, concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. Dotted and dashed lines on maps represent approximate border lines for which there may not yet be full agreement.

The mention of specific companies or of certain manufacturers' products does not imply that they are endorsed or recommended by WHO, including TDR, in preference to others of a similar nature that are not mentioned. Errors and omissions excepted, the names of proprietary products are distinguished by initial capital letters.

All reasonable precautions have been taken by WHO, including TDR, to verify the information contained in this publication. However, the published material is being distributed without warranty of any kind, either expressed or implied. The responsibility for the interpretation and use of the material lies with the reader. In no event shall WHO, including TDR, be liable for damages arising from its use.

Contents

I. PREFACE	<u>iv</u>
II. ACKNOWLEDGEMENTS	<u>v</u>
III. ABBREVIATIONS	<u>vi</u>
IV. EXECUTIVE SUMMARY	<u>vii</u>
V. BACKGROUND	<u>1</u>
VI. PROCESS	<u>3</u>
VII. PUBLIC ENGAGEMENT	<u>4</u>
VIII. HOW CROWDFUNDING WORKS	<u>5</u>
IX. STEPS IN CROWDFUNDING FOR RESEARCH	<u>6</u>
PRE-CAMPAIGN	<u>6</u>
1. Define the scope of the study	<u>6</u>
2. Identify the campaign audience	<u>6</u>
3. Plan & design the campaign strategy	<u>7</u>
DURING THE CAMPAIGN	<u>10</u>
4. Launch the campaign	<u>10</u>
5. Update the audience	<u>10</u>
POST CAMPAIGN	<u>10</u>
6. Foster relationships	<u>10</u>
X. STRENGTHS, WEAKNESSES, OPPORTUNITIES AND THREATS OF CROWDFUNDING	<u>11</u>
XI. OPEN ACCESS RESOURCES	<u>12</u>
XII. ANNEX: EXAMPLES FROM TDR OPEN CALL FOR CROWDSOURCING FINALISTS	<u>13</u>
ANNEX 1: ZIKA CAMPAIGN IN THAILAND	<u>13</u>
ANNEX 2: LEISHMANIASIS CAMPAIGN IN SRI LANKA	<u>15</u>
ANNEX 3: SCHISTOSOMIASIS CAMPAIGN IN NIGERIA	<u>17</u>
XIII. REFERENCES	<u>19</u>

I. Preface

Public engagement is increasingly recognized as an important part of science. Robust community involvement can spur innovation, meaningfully connect with local communities and improve health outcomes. Recognizing this change, many major science funders now require public engagement in research studies. How can we organize more effective public engagement in research? In addition, how can this engagement drive crowdfunding for research? We define crowdfunding as the process of engaging large groups of people who make monetary and non-monetary contributions to a research study. These two questions have inspired a new practical guide on public engagement and crowdfunding in research.

This practical guide provides tools, open access resources and advice for researchers, especially those living in low and middle-income countries (LMICs). The practical guide was piloted and tested by TDR Global, a worldwide community of passionate scientists and experts who have been working with TDR on research on infectious diseases of poverty. The practical guide was developed by a group of stakeholders and experts convened by TDR, Special Programme for Research and Training in Tropical Diseases, the UNICEF/UNDP/World Bank/WHO. The project was organized by TDR Global, SIHI (Social Innovation in Health Initiative) and SESH (Social Entrepreneurship to Spur Health).

Two things strike me about this new practical guide: First, the vision of scientific engagement and crowdfunding sketches out a fundamentally different relationship between researchers and the public. Instead of having expert outsider researchers providing answers, it asks researchers to work side by side with communities to design, implement and evaluate new ideas. This exciting and important approach could make scientific research more locally accountable. Second, innovative financing mechanisms to support LMIC research are urgently needed. Crowdfunding methods could help to support horizontal connections, introduce researchers to donors and decolonize some aspects of research funding.

The Public Engagement and Crowdfunding in Health Research: A Practical Guide provides a map for researchers, innovators, community members and others on how to organize public engagement in preparation for research crowdfunding. This practical guide complements [a global qualitative evidence synthesis](#) from the same team, TDR/SESH/SIHI [Social Innovation Monitoring and Evaluation Framework](#) and the TDR/SESH/SIHI [Crowdsourcing for Health and Health Research Practical Guide](#).

This practical guide is ultimately a call for action. Among researchers in LMICs, this underlines the need for more creative public engagement to support research studies. The tools and open access resources exist and can provide momentum to improve engagement. Among universities and other institutions, providing support for organizing crowdfunding projects can accelerate donations and build networks. Finally, among funders, this practical guide suggests crowdfunding could be one pathway to making science more accountable, transparent and community-engaged.

John Reeder
- Director, TDR



II. Acknowledgements

This practical guide was developed through a collaborative process of public engagement led by TDR Global. TDR Global is a worldwide community of passionate scientists and experts who have been working with TDR on research on infectious diseases of poverty.

Our core team included Priyanka Shrestha, Clarisse Sri-Pathmanathan, Sana Navaid, Eneyi Kpokiri and Joseph D. Tucker. Our working group included the following individuals (in alphabetical order): Meghan Boren, Chelsea Deitelzweig, Noel Juban, Mary Ann Lansang, Pascal Launois, Miguelhete Lisboa, Don Mathanga, Renata Mendizabal, David Routh, Mahmud Ali Umar, Asha Wijegunawardana and Teerawat Wiwatpanit. Our end user group included the following individuals (in alphabetical order): Emmanuel Ahumuza, Jackeline Alger, Ogechukwu Benedicta Aribodor, Ana Gerlin Hernandez Bonilla, Obinna Ikechukwu Ekwunife, Noah Fongwen, Debra Jackson, Meredith Labarda, Barwani Msiska, Chukwu Okoronkwo, Wachinou Ablo Prudence, Weiming Tang, Shufang Wei, and Dan Wu. Our internal TDR Global peer reviewer was Sassy Molyneux. Our public peer reviewers were Kathleen Agudelo,

Chinyelu Angela Ekwunife, Elizabeth Osim Elhassan, Hewawasam Enderage Chandana Sampath Kumara, Chukwu Okoronkwo, and Omolola Olojede. The group would also like to acknowledge support from Michael Mihut, Pascal Launois, Makiko Kitamura at TDR and Mia Hoole, Tina Fourie, Debashree Majumdar, Jean Barcena, and Qinyi Liu for communications assistance.

This practical guide resulted from a collaboration between TDR Global, SESH (Social Entrepreneurship to Spur Health), and SIHI (Social Innovation in Health Initiative). The work received support from the TDR, the Special Programme for Research and Training in Tropical Diseases, co-sponsored by UNICEF, UNDP, the World Bank and WHO. TDR is able to conduct its work, thanks to the commitment and support from a variety of funders. These include our long-term core contributors from national governments and international institutions, as well as designated funding for specific projects within our current priorities. For the full list of TDR donors, please visit TDR's website at <https://tdr.who.int/about-us/our-donors>. TDR receives additional funding from Sida, the Swedish International Development Cooperation Agency, to support SIHI.

III. Abbreviations

LMIC	Low and middle-income country
-------------	-------------------------------

NCCPE	National Co-ordinating Centre for Public Engagement
--------------	---

NHS	National Health Service
------------	-------------------------

SESH	Social Entrepreneurship to Spur Health
-------------	--

Sida	Swedish International Development Agency
-------------	--

SIHI	Social Innovation in Health Initiative
-------------	--

WHO	World Health Organization
------------	---------------------------

TDR	UNICEF/UNDP/World Bank/WHO Special Programme for Research and Training in Tropical Diseases
------------	---

IV. Executive Summary

Public engagement is essential for high-impact scientific research. Public engagement in research is a bi-directional communication between the researcher and the public for mutual benefit. The public are people in general and especially the local community. Public engagement involves communication and advocacy with the public over time, demanding a strong understanding of the local setting. It adds scientific, practical and ethical value across the lifespan of a research study and is a prerequisite for crowdfunding for health research. We define crowdfunding for research as the process of engaging large groups of people who make monetary and non-monetary contributions to a research project. Crowdfunding requires a creator passionate about the research, networks of potential supporters, and an organizer.

The following consensus statement provides practical tools and suggestions for public engagement and crowdfunding, with a focus on LMICs:

General principles related to public engagement to lay the foundation for crowdfunding for research

1. Public engagement is a dynamic process that requires sustained relationships with key stakeholders in the local community.
2. Partnerships with people affected directly or indirectly by the topic and experts from the local community can build powerful networks, empower communities, develop messages, and establish a rationale for public support.
3. Diverse communication materials that are easily understood by the local public and inclusive of key groups are important for public engagement.
4. Co-creation of messages with the public provides a mechanism to iteratively engage people, refine potential crowdfunding campaign materials, increase acceptability, and foster transparency and accountability.

5. Open access resources provide frameworks and tools to facilitate public engagement in research.

Crowdfunding for research

6. Crowdfunding is a multi-stage process that includes creators (researchers creating the campaign), backers (people providing both monetary and non-monetary support) and organizers (groups linking creators and backers).
7. Potential advantages of crowdfunding for research include the following: less reliance on traditional funders; nurturing local, horizontal connections and relationships; expanding public engagement strategies; and potential for raising money for research.
8. Potential modifiable risks of crowdfunding identified in the qualitative evidence synthesis include lack of standardized peer review, inability to monitor research funding allocation post-campaign, and fewer protections against fraud and falsification.
9. Some important considerations before launching a crowdfunding campaign include the following: finalizing the public engagement strategies and their dissemination plans; assigning promotion responsibilities; identifying and engaging an organizer; finalizing the budget for the campaign; preparing all stages of the campaign; and creating post-campaign plans.
10. The characteristics that increase the likelihood of successful crowdfunding for research include the following: strong links to multiple networks related to the research focus; robust institutional champions and organizers; a clear rationale for public involvement; strong government support; approval from ethical review committee and related institutional approvals; and appealing storytelling embedded within the campaign.

Pre-campaign

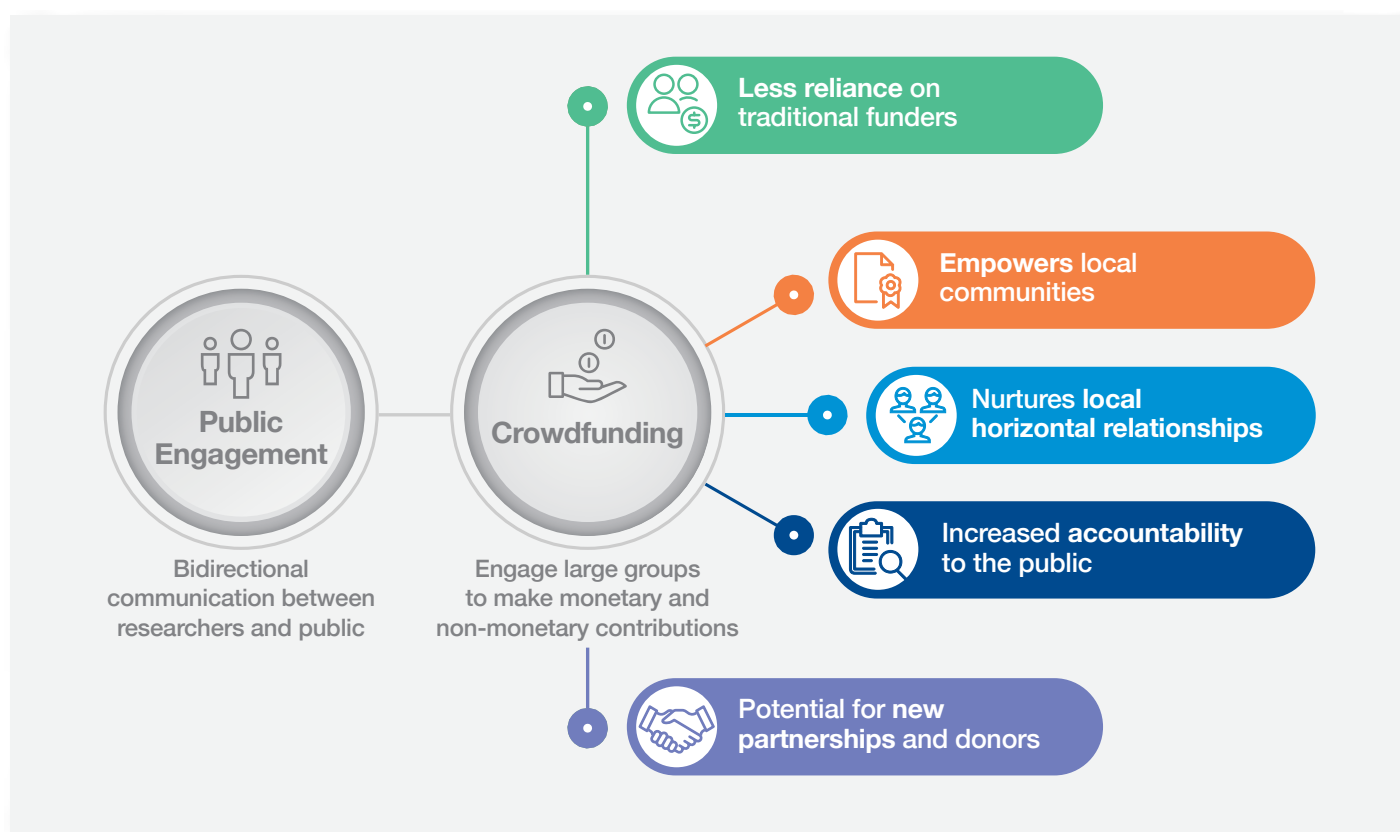
11. Create a detailed plan for public engagement across the entire life of the campaign. This includes plans to promote and design the campaign through online digital strategies and offline or in-person strategies. Consideration of translation into local languages is important.
12. Listen to end users and people affected by the problem to describe the impact of the problem on the local community. Provide opportunities for community-led action on research findings.
13. Identify professional, personal and other networks who may be interested in donating to the crowdfunding campaign and design events to discuss with potential backers.
14. Organize user testing to refine the campaign plan, including pilot testing campaign materials and public engagement strategies among local community members. This can also inform when to launch the campaign.

During the campaign

15. Speak at public events, use conventional media, and create digital messages to promote the campaign and draw attention to the cause by sharing with personal and professional networks.
16. Consistently communicate clearly, concisely, and if possible, in the local language of the intended audience.
17. Update the public on progress related to the campaign through text or video messages.

After the campaign

18. Report back on research progress to the backers and fulfill obligations in the campaign strategy.
19. Disseminate findings of the research study to the public, local government authorities, and other key stakeholders using open access methods.
20. Foster new research relationships and continue public engagement, focusing on the local community and building horizontal relationships.



V. Background

Financing infectious diseases of poverty research in LMICs is often difficult. In response, a Sri Lankan research team decided to use crowdfunding to raise money for a community-based Leishmaniasis study. Despite competing demands from COVID-19, the team raised \$7,244 to evaluate a community health intervention designed to improve community awareness about Leishmaniasis and enhance adult sand fly vector control and surveillance (Annex 1). During COVID-19, another crowdfunding study raised € 2.3 million, resulting in a cluster randomized controlled trial published in the *New England Journal of Medicine*.¹

Crowdfunding is the process of engaging large groups of people who make monetary and non-monetary (e.g., in-kind contributions, communications support) contributions to a health research project in this context. It can help mobilize local resources, democratize research, enhance South-South collaboration and increase research accountability. A global qualitative evidence synthesis found that crowdfunding builds

bidirectional communication between researchers and the public.² This can increase the public's trust, awareness and understanding of science.

Public engagement is a two-way communication process in learning and engaging with the public for mutual benefit.³ Public engagement in research includes producing new ideas, sharing information, forging local and global partnerships and enhancing research methods. Public engagement is increasingly recognized as an essential component of scientific research because the public are patients, funders and research participants.⁴

The purpose of this practical guide is to build capacity for researchers, innovators and students to enhance public engagement and consider crowdfunding. It is designed to be relevant to people in a broad variety of settings, regardless of experience with social media or Internet bandwidth. We are particularly interested in supporting crowdfunding in resource-constrained settings.



Some key definitions are provided below:

Key Terms	Definitions
Audience	individuals or groups who are either directly related to the creator or interested in the project
Backers	representatives who fund part of the campaign through a monetary donation, also known as donors
Beneficiaries	members of the community who will benefit from the campaign (also referred to as end users)
Campaign	a set of organized activities led by the creator to appeal for funding from the public
Creators	researchers, innovators, or students requesting financial support from the public for their research
Institutional champion	people at the creator's institution who support the research cause
Networks	personal, professional and other relationships between the creator and the public
Organizers	a group that hosts the campaign and bridges the creators and their potential backers. Potential organizers include platform-based private companies, research universities and community organizations
Platforms	online-based applications hosted by an organizer
Public	relating to people in general and especially the local community
Supporters	broader network of people who contribute to a project, including backers, beneficiaries, and others

VI. Process

This practical guide was developed following a three step-process including an evidence review,² consensus development and public peer review. The practical guide was developed by TDR Global members in partnership with SESH and SIHI.

The evidence synthesis included a global scoping review and qualitative synthesis of the evidence.² The evidence synthesis was written by the core team and received feedback from the 12-person working group. Each working group member had experience with LMIC public engagement or crowdfunding. They included academic researchers, development experts, social innovation leaders. Eight of the 12 members were living in LMICs. An end user group of 14 individuals with a health, social innovations, or public engagement background was solicited for the co-creation of this guide in order to gain a diversity of perspectives on its use and implementation. Twelve of the fourteen members of the end user group were living in LMICs. All participants declared no potential conflicts of interest.

The consensus process included a Delphi survey to incorporate comments from both the working and end user groups. Multiple virtual meetings were organized to discuss the feedback.

The groups iteratively improved the document based on written feedback and videoconferences. Within the executive summary, all statements that received greater than 90% agreement were included in the final version.

A public peer review process was organized by calling for public volunteers to become reviewers for the guide. The call for public reviewers was shared on social media and disseminated across TDR Global, SIHI and SESH networks. Six public peer reviewers from Nigeria (4), Sri Lanka (1) and Colombia (1) provided feedback.

The core team made final revisions to the document incorporating contributions from final meetings and discussions.

VII. Public engagement

Public engagement is an essential component of all research studies. Some common strategies for effective public engagement include the following: defining a community-based network with shared interests; co-creating research materials; developing diverse messages appropriate for the public; and engaging with key stakeholders.

Identifying the right group of people that share common cultural and scientific interests is the first step towards building a network. This network could include people living with the disease, community organization representatives, health professionals, researchers, government leaders and others who have a genuine interest in the cause.

Once the network has been built, it is important to share and carefully explain the research purpose, rationale and contribution for the greater good. The researcher and the community can iteratively co-create content related to the research (for example, recruitment materials, educational materials). Co-creation is defined as an iterative, bidirectional process between researchers and the public. Pilot testing study materials can help build trust with potential community supporters. Before the study, the researcher should work with end users and local communities to frame the research and clarify the objectives.

Diverse messages that are authentic and inspirational are important to reach the network. Text describing the message can be enriched and supplemented by images, infographics, audio-visuals, videos, songs and blogs. An infographic is a visual representation of data/information. Moreover, ensuring a range of engagement tools can invite more enduring attention to the study.

Engaging key stakeholders is also a fundamental component of public engagement. Key stakeholders may include personal, alumni, cause-specific, institutional and professional networks. Initial engagement could include community lectures and talks, print and traditional media (newspapers, TV, community radio), podcast and audio features to attract individuals and build trust. Public engagement can be organized in schools, market places and locally suitable gatherings such as churches or other places of worship and community interaction.

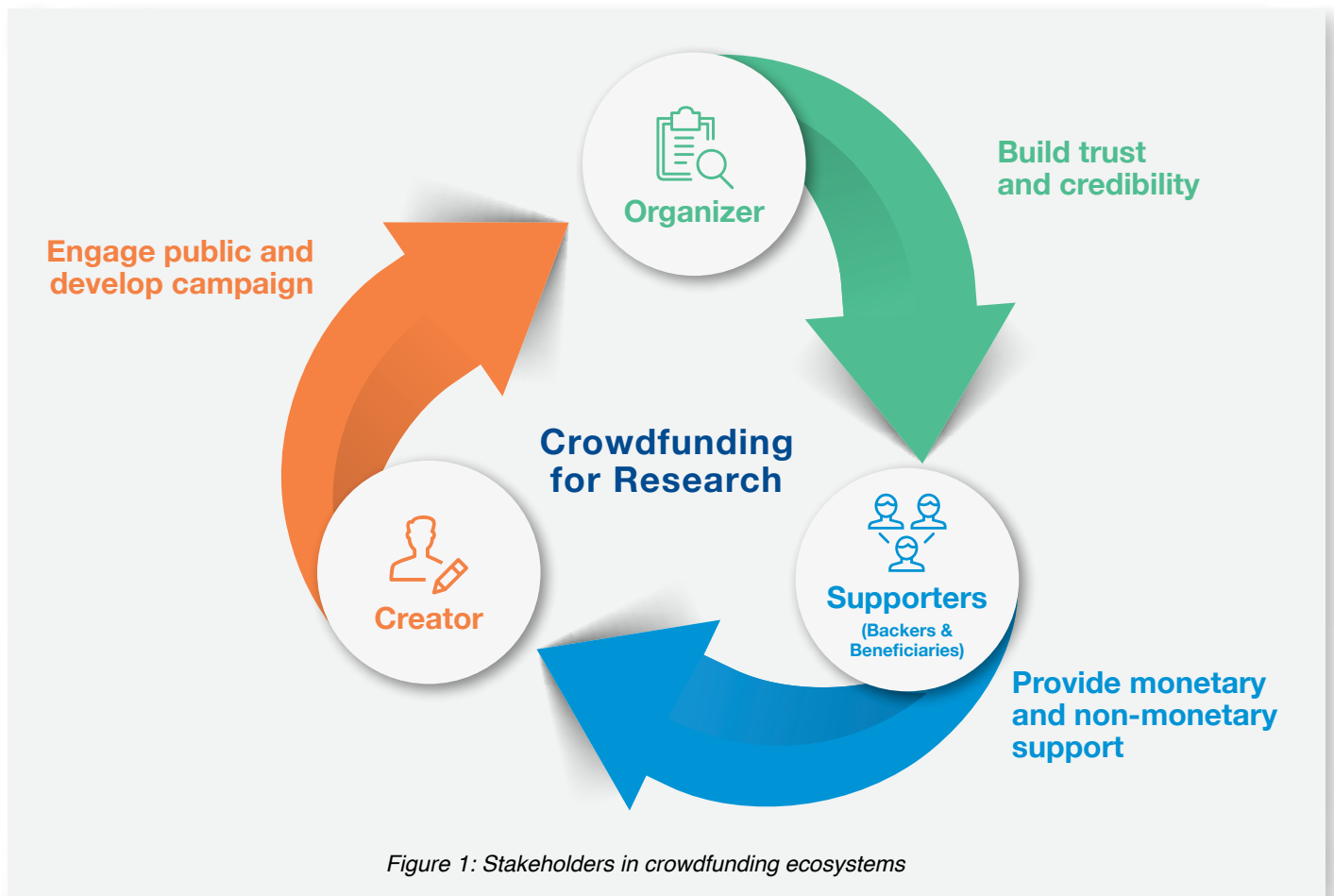
Public engagement may also create a network for future collaborations and does not necessarily need to be followed by crowdfunding. Robust public engagement, however, does establish a foundation for crowdfunding. Evidence shows that early-stage high-level networking, regular communication and targeted dissemination are important to ensure a crowdfunding campaign's success.



VIII. How crowdfunding works

Crowdfunding is a multi-stage process that engages three key groups: creators, supporters (both backers and beneficiaries), and organizers (see Figure 1). The traditional crowdfunding campaign process predominantly takes place online, where the creators develop their content

and liaise with the relevant crowdfunding organizer to promote and seek financial support from the backers. However, in-person interactions and involvement with the public are a significant part of the campaign process.



There are two types of crowdfunding models: “all-or-nothing” and “keep-what-you-raise”. In the all-or-nothing model, once the crowdfunding target and time-period is set, the creators only receive the funds if they successfully raise their targeted amount within the specified period. In the keep-what-you-raise mode, they can keep the amount of money that is raised, regardless of whether they achieve their target.

The all-or-nothing model, although it does not provide financial security to creators, has been proven to be more successful as it provides backers with more confidence in the project. Although the keep-what-you-raise model often seems safer to creators, it has, however, lower success

rates and in some cases the organizer might charge a fee regardless of what has been raised. This model is more popular among charities and non-profit organizations. Most research crowdfunding uses either donation-based or reward-based models. Donation-based crowdfunding is philanthropy-based where the backers fund the project without expecting anything in return, while the rewards-based model promises some non-financial products or rewards in exchange of their investment. Most scientific research and health-based projects generally follow the donation-based crowdfunding model because of their non-profit and non-commercial nature and their pledge of relatively small funds.

IX. Steps in crowdfunding for research

The steps below outline the crowdfunding process prior, during, and following the crowdfunding campaign. Figure 2 provides an overview of public engagement strategies in each of these steps in a crowdfunding campaign process.

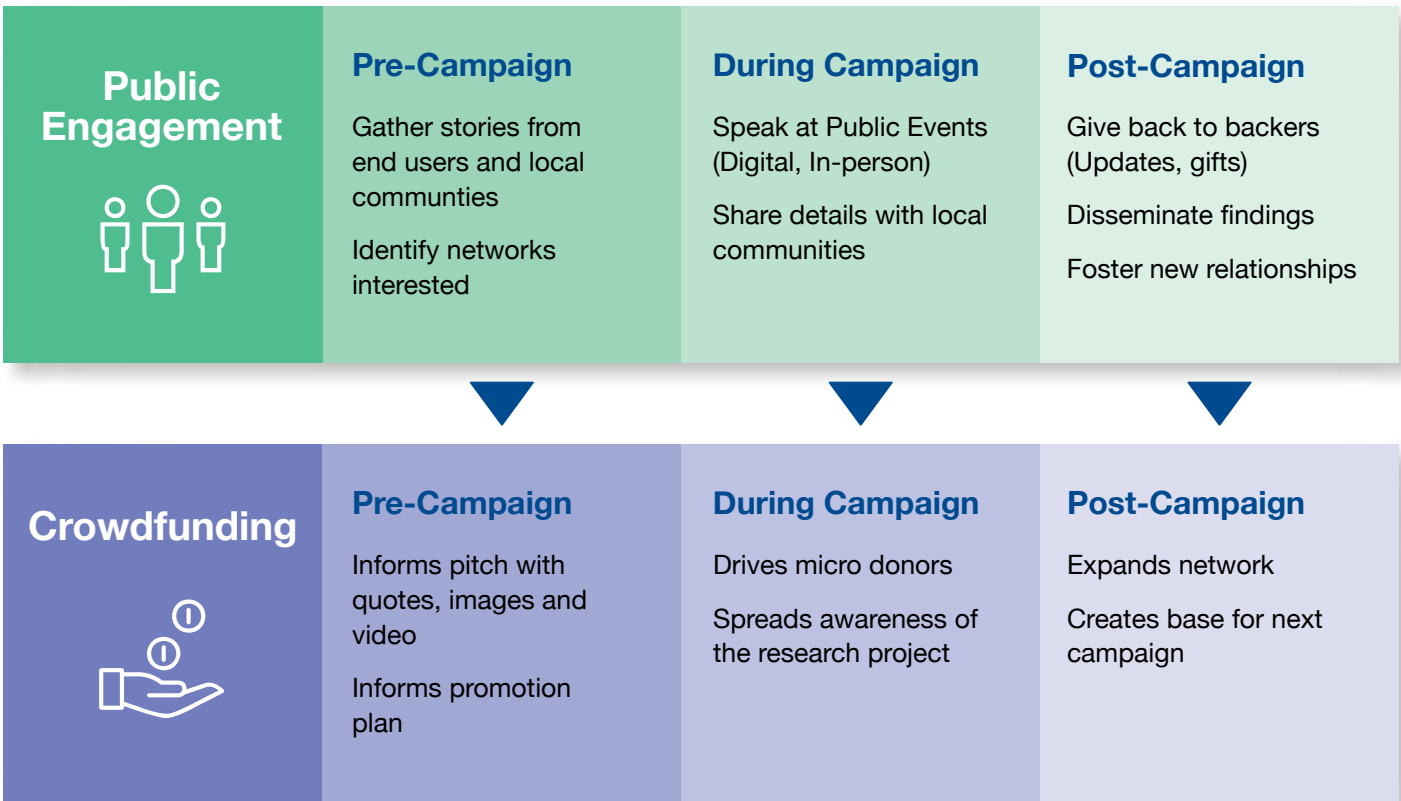


Figure 2: Public engagement prior to, during and after the campaign

Pre-campaign

1. Define the scope of the study

Prior to launching the campaign, the crowdfunding study should be defined and contextualized. Discussions with experts and key informant interviews can increase the rigor of the science. It is essential to engage with the end users or beneficiaries community of the project to build trust in the study and campaign. Reading what is already published in the mainstream media, how well-informed the public is about the topic as well as what relevance the project will provide to the broader context must be ensured.

2. Identify the campaign audience

Backers are critical to lead a successful crowdfunding

campaign. They are individuals or organizations who share common interests and a sense of belonging to the community related to the research team, the idea and the institutions. Mapping out the potential audience within and beyond the local context early is important. For instance, one could campaign in collaboration with groups in different regions working on the same disease of interest. Identifying diverse stakeholders who share common interests and collaborating with them to identify public engagement channels is paramount. Working with institutional champions and universities are useful ways to achieve wider reach. Key stakeholders could include patients and the public, providers, purchasers, payers, policy-makers, product makers and principal investigators.

3. Plan & design the campaign strategy

Once the overall idea and audience are finalized, a more specific campaign strategy can be established. Some important considerations to plan and build the campaign strategy include the following:

a) Create a plan for engagement

Communication is key in crowdfunding campaigns; therefore, you need to choose engagement strategies that will move the audience or spark their interest. Developing the campaign information, a video pitch,

rewards (if necessary) and familiarizing with communication platforms are basic considerations while planning a campaign. Having additional support from organizations such as hospitals, academic institutions, research centers, scientists (local and international) and public institutions is equally rewarding.

For instance, advice can be solicited on crafting the campaign and dissemination of materials or information from communications experts in these institutions. Some key elements are described in Figure 3.

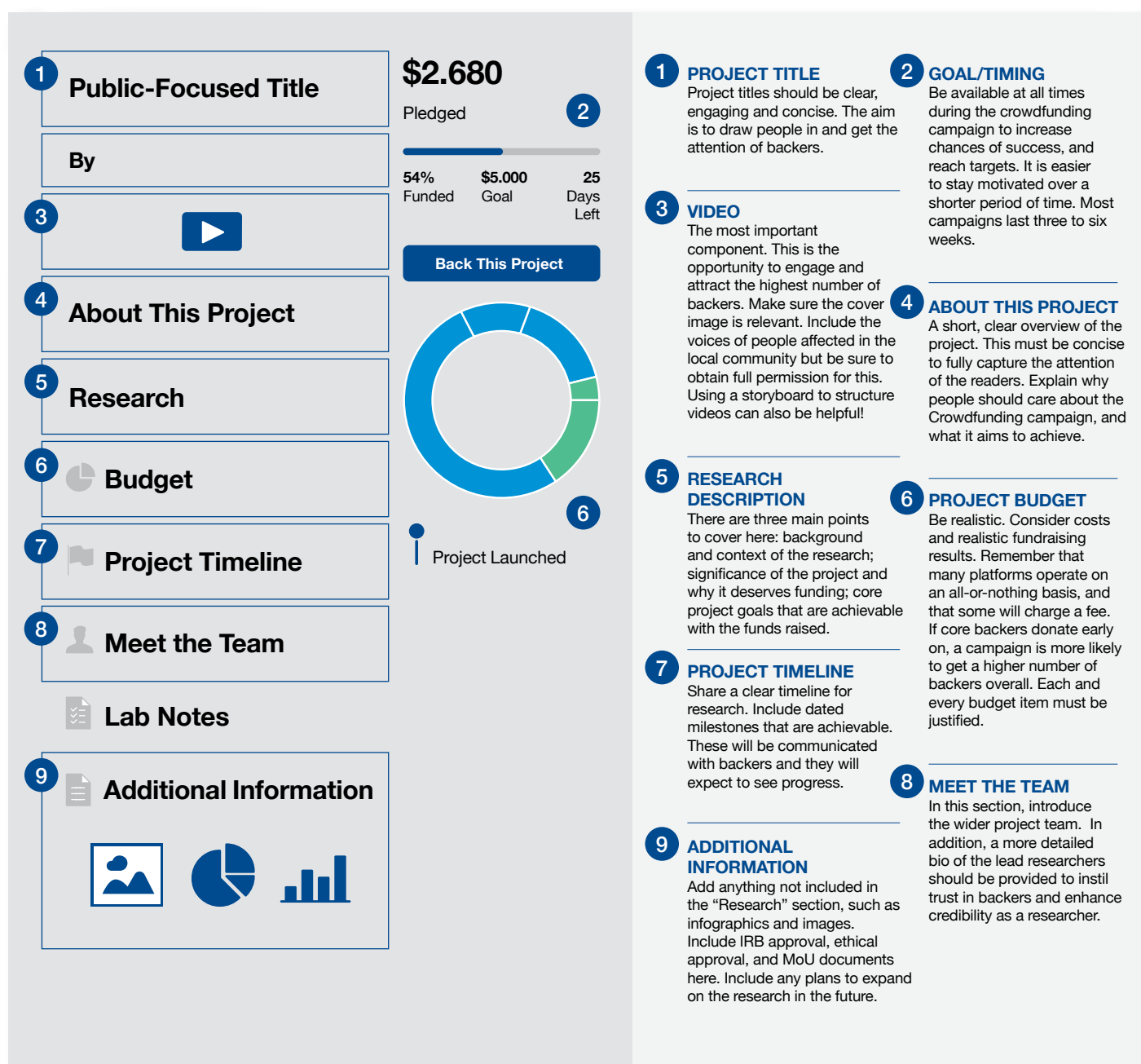


Figure 3: Anatomy of a crowdfunding campaign with its essential components (adapted from Experiment.com)

The campaign information should be clear, avoid jargon and capture the element of *why* instead of the technicalities of *how* the project is being conducted. It must appeal to the general public because this is the foundation for the campaign. Furthermore, when indicating the amount of desired funds, being realistic and transparent can help to ensure trust and clarity among supporters.

Creating a video is a useful way to connect with the audience on a more personal level. A good video has an engaging storytelling component. Some important considerations include the length, sound, language and content of the video:

- ✓ A video must be short and should grasp the public's attention.
- ✓ Selecting appropriate music or sound, keeping the video quality clean and addressing the funding target and/or requests for other types of contributions are essential.
- ✓ Incorporating local languages in the video as subtitles can expand the campaign's reach. Some creators may prefer to use their local language and use English subtitles instead.
- ✓ Including quotations and testimonials from beneficiaries can be helpful to contextualize the research.

Most crowdfunding for research campaigns do not have tangible rewards, but they can provide an opportunity to add value and attract more supporters. Rewards can come in the form of products, services and recognition. Acknowledgements in publications, written thank-you postcards, photographs of the community, community-created crafts or recognition in social media are all meaningful rewards.

When planning and preparing for the campaign launch, it is important to keep track of the budget and expenses. A transparent budget is a show of accountability for the backers. Planning the budget using spreadsheets or other project management tools to keep a record of resources needed and up-to-date expenses are useful approaches. For instance, keeping note of the cost of rewards, platform charges, communications and travel expenses, among others can be helpful. Including a financial report from the host organization can be useful.

Once the audience is studied and identified in Step 2, a clear record of the network must be kept: categorize contacts, identify potential influencers and create mailing lists. These networks could be initiated through reaching out to current/former colleagues, friends and family, social media as well as open events and forums engaging students, researchers, local public and bloggers.

b) User-testing the campaign

Before launching the campaign, testing out the ideas with the potential backers may enhance engagement. Evidence suggests that bidirectional communication between researchers and the public can bridge the gap between science and society, spurring engagement. It is worth obtaining feedback from beneficiaries, potential backers, and institutional champions to quantify the impact of the problem on the local community.

c) Choose a crowdfunding organizer

Crowdfunding organizers are groups that host campaigns and connect creators to potential backers. Organizers may be external (open for anyone), internal (e.g., university/institution-based), or a hybrid of external and internal (Annexes 1, 2, 3). More details are provided in Table 1.

Table 1: Advantages and disadvantages of using external, internal and hybrid-led organizers for a health research crowdfunding campaign.

Organizer	Advantages	Disadvantages
External (Online-based private platform)	Ease of campaign organization: funds are collected from donors through the platform. Transparency: all the required information is clearly displayed on a well-designed online page. Platforms may increase a campaign's exposure, especially if the platform is dedicated to health research. Advertising: improved ability to link the campaign to social media and gain media attention. All-or-nothing models protect researchers if they are unable to reach their targets.	High organizer fees (can range from 5 to 9% of the final amount raised). Payment processing fees (usually around 3% of each donation). Freedom to organize and advertise the campaign is limited to the platform and website layout. Difficult to incorporate cash donations and involve individuals offline. The campaign is published amongst many other campaigns on the platform, which could distract funders away from the research.
Internal (University or other institution)	Most universities that offer researchers to crowdfund their projects are all-or-nothing, meaning there is a higher guarantee that the research will come to fruition. Institutional backing can improve funders' trust in the researchers and their projects. Ease of communicating with backers and advertising the campaign through a recognized online page.	Only university-registered researchers can apply to raise funds. Institutions also have processing fees and administrative charges. Funding targets tend to be very high and unsuitable for smaller pilot projects. Difficult to incorporate cash donations and involve individuals offline. Maybe more difficult to engage backers that are not affiliated to the institution.
Hybrid platform (online+institution/others)	Higher credibility for the campaign. Both monetary and non-monetary support such as providing access to contacts and media outlets outside the platform reach. Higher promotion and prestige for the institution as a result of engagement in research advocacy. Ability to collect funds through various modalities (international transfer, cash donations, online transfers) with the support of the institutional departments.	The researcher has a stake of institutional reputation and therefore must display the campaign information and targets in an accessible and transparent way. No standardized way to regularly communicate and share results with backers received from two different channels. Difficult to track the identity of offline backers.

During the campaign

4. Launch the campaign

After the campaign plans have been finalized and the ethical review committee approval has been obtained, the campaign can be launched. Following the launch, assessing social media analytics related to initial promotion messages can help to tailor content.

5. Update the audience

An important part of campaign management is also providing information on the status of the project to the

backers which may include updates on budget, funding targets and research outputs through online updates and/or in-person meetings. This phase demands a significant amount of effort and attention from creators who must ensure they respond promptly. Connecting regularly with the public allows opportunities for creators to better understand their audience. Furthermore, sustained engagement helps build awareness about the research topic.

Post campaign

6. Foster relationships

Once the campaign ends and the results are finalized, the creator delivers on commitments such as sending rewards to backers, disseminating research findings, and nurturing local relationships.

After the campaign, there is an exciting opportunity to collaborate with the resulting network to potentially co-create new research projects.



X. Strengths, weaknesses, opportunities and threats of crowdfunding

	Positive	Negative
Internal	Strengths May be especially well-suited for early career researchers and early-stage pilot studies Relatively cheaper and quicker way of funding research compared to traditional fundraising approaches and lengthy scientific grant applications Provides an opportunity for the researcher to be directly accountable to public backers Open to any research topic without eligibility criteria	Weaknesses Limited awareness of crowdfunding concept and organizers among the locals and backers in LMIC settings Most organizers charge 5-10% of administrative and payment processing fees Only suitable for raising small amount of funds Likely to miss out supporters with limited/no access to internet and those reluctant to provide credit card information online if not approached through physical campaigns
External	Opportunities Crowdfunding helps to democratize research and validate ideas on topics unexplored to expand the research landscape, particularly focusing on LMIC settings Campaigners can grow their network and establish professional relationships for further research Suitable avenue for researchers to conduct pilot/baseline research for preliminary data and support their project to apply for larger research grants Although online-based campaigners can gain popularity through using other non-Internet-based channels such as university groups, community programmes, radio programmes, etc. Provides an opportunity to receive external feedback from backers, experts, and others May be particularly useful for women who sometimes face structural barriers in research grant applications	Threats Few organizers (especially platforms) focused on LMIC researchers In the absence of rigorous peer review process, crowdfunding may be criticized for projects with poor scientific merit Gaining public trust is difficult due to perceived risks of fraud and deception as well as unfair allocation of funds Most organizers are based in high-income countries with well-developed transaction processing routes. In absence of accessible and functional credit cards, it becomes difficult for campaigners and backers in LMICs to collect and provide funds respectively Lack of proper government regulations in documentation and funds processing in LMICs

XI. Open access resources

Understanding public engagement (English)

- [Tools for talking about public engagement](#): a guide developed by the National Co-ordinating Centre for Public Engagement to understand public engagement and why it matters for researchers
- [Planning public engagement activities](#): a one-page guide on public engagement for researchers developed by the Wellcome Trust
- [Public engagement: a practical guide](#): a guide from the National Institute of Health Research on public engagement; including scoping, planning, executing and disseminating information
- [National Co-ordinating Centre for Public Engagement](#): open access tools, resources, and suggestions for public engagement in research
- [How to make your research jump off the page: Co-creation to broaden public engagement in medical research](#): a description of how co-creation can enhance public engagement, including open access resources on creating video and infographics

Public engagement using social media (English)

- [What Works: Engaging the public through social media](#): a tool for using digital media effectively for public engagement for researchers by the National Co-ordinating Centre for Public Engagement
- [Guidance on the use of social media to actively involve people in research](#): INVOLVE/NIHR guidance on using different types of social media for research as well as their benefits, challenges, risks and ethics
- [The use of public engagement for technological innovation](#): a research report synthesizing recent evidence, in the form of a literature review and case studies, on the use of public engagement for technological innovation
- [Crowdfunding video creation](#): an article with tips and resources on making crowdfunding videos

Understanding crowdfunding in research (English)

- [Advances in crowdfunding research and practice](#): an open access book that presents a comprehensive and up-to-date collection of knowledge on the state of crowdfunding research and practice
- [Raising money for scientific research through crowdfunding](#): an article introducing crowdfunding and advice for scientists looking to fund their research

Understanding crowdfunding for community projects (English)

- [Crowdfunding Good Causes](#): a report to guide on the opportunities and challenges in crowdfunding for charities, voluntary organizations and social enterprises
- [Crowdfunding Guide](#): a stepwise guide on learning, building, marketing, executing campaign tips for non-profits, charities and social impact projects
- [Crowdfunding Program](#): a detailed report from the University of California, Berkeley with tools, tips and best practices on crowdfunding from planning to execution of the campaign

Other resources

- [TDR Global/SESH Global Crowdfunding Challenge Contest \(English\)](#)
- [TDR Global crowdfunding open call finalist – Sri Lanka](#)
- [TDR Global crowdfunding open call finalist - Thailand](#)
- [TDR Global crowdfunding open call finalist - Nigeria](#)
- [Role of Managers in Ensuring the Sustainability of Crowdfunding Platforms \(English\)](#)
- [Public engagement and crowdfunding for health research: A global qualitative evidence synthesis and TDR pilot](#)

XII. Annexes:

Examples from TDR open call* for crowdfunding finalists

**TDR Global organized a crowdsourcing contest to solicit research proposals from LMIC researchers and then provided training and mentorship to selected finalists to build capacity for crowdfunding. A total of 121 researchers from 37 countries submitted proposals to the challenge contest. Five finalists were identified, matched with 10 TDR Global mentors, and were given public engagement training to prepare them for crowdfunding.*

1. Zika campaign in Thailand



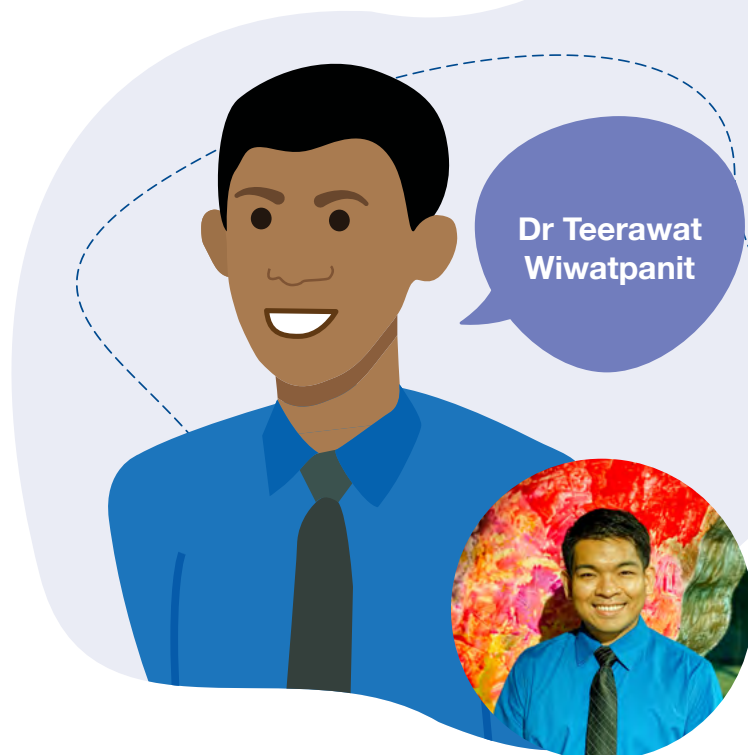
Title

Modeling Zika virus transmission from mother to child using uterine mini-organs - Dr Teerawat Wiwatpanit



Purpose of the campaign

To raise initial funds for a cell culture platform in order to study mother-to-child transmission of Zika virus



Pre-campaign activities

Prior to attending the capacity-building workshop on crowdfunding for researchers hosted by TDR Global, I created social media accounts (for example, [Twitter](#)) in order to engage online networks. I also started engaging with well-known scientists in the field (namely mosquito-borne infections, tissue engineering, female reproductive science), my former colleagues, advisors from Ph.D. programmes and related journals.

Once I had created my base of followers, I started posting updates on the TDR Global crowdfunding challenge contest, the workshop and preparations for crowdfunding pitches. I created a blog (<https://busymosquitoes.blogspot.com/>) to showcase our lab, experiments and introductions to crowdfunding for scientific research.

My research team published contents on this website at least once a week. At the end of each post, I always included a small paragraph reminding the readers about our upcoming crowdfunding campaign.

After the capacity building workshop with TDR Global, I contacted my institution's public relations office to update them on the crowdfunding campaign. I also asked for their help in filming the video pitch for the campaign and they connected me with their camera crew.

After preparing substantial pre-campaign materials, I started reaching out to my friends, family members, current and former colleagues to inform them about the upcoming crowdfunding campaign.

During campaign activities

Once the campaign was launched, I remained very active both on my social media accounts and the [campaign page](#). Then, I compiled a mailing list of potential donors (friends, family members, colleagues and alumni networks from my US high school, college and Ph.D. programmes).

On the launch day, I sent them an email to introduce the crowdfunding campaign. I posted once or twice a day on Twitter to advertise the campaign and asked for pledges. I updated the campaign website a couple of times a week (under “Labnotes” section on the website), which then was shared on all my social media accounts. In order to attract more attention, I created a TikTok account and posted funny short clips about our work—how we set up experiments, how we prepared samples for the microscope and shared pictures of our 1-ft tall mosquito model in the lab.

These types of contents were also well-received on Twitter and Facebook. I also reached out to my social media influencer and blogger friends to share my campaign page. They agreed to post about our crowdfunding page.

Post campaign activities

After the campaign was successful, I reached out to my audiences on social media and mailing list to share the good news and thank them for their support. I remained relatively active on my academic social media accounts as well as on the campaign page (Experiment.com) that allows you to keep your campaign page active even after the campaign is over and use it to connect with your donors. I continue to post updates on my research progress but not as frequently as during the campaign.

Monetary support

Within the 45-day campaign period, the goal was to raise \$8,000. We received a total of \$8,180 from a total of 130 donors. The average fund pledged was \$62.

Non-monetary support

We received support from the institution’s public relations team for filming and editing of the final video pitch. We

and even made their followers share it until it showed up exclusively on the Facebook account reaching over 2 million followers. This one post helped us raise a significant amount of funds overnight. Communications were handled depending on the type of audience. For those on the mailing list, more official messages were sent than with other social media outlets. The email would include a weekly update on the campaign (number of donors and how many pledges collected) and lab updates.

In addition to the online strategies, our institution’s public relations team connected me with the local news stations for interviews. We realized that a lot of people wanted to help but were not comfortable giving out their credit card information online, did not own a credit card or readily had access to the Internet.

Therefore, we set up a booth to collect pledges and cash donations at events in various on-site locations including farmers’ markets and science conferences (during the pre-pandemic phase) that contributed to a big portion of the raised funds.

also received help from the public relations team to identify local news outlets for interviews and in-person events to showcase the crowdfunding project. In-person events provided an opportunity for on-site donations.



2. Leishmaniasis campaign in Sri Lanka



Title

Community-based Leishmaniasis Research in Sri Lanka - Dr Asha Wijegunawardana



Purpose of the campaign

To monitor and control leishmaniasis using the Mobile Vector Surveillance Unit (MVSU)



Pre-campaign activities

I learned about crowdfunding projects and gathered information to incorporate into my campaign. Then I built a campaign team, including three students, two interns, five colleagues from my institution, and five members from other relevant government institutions. As a result, I collaborated with colleagues in my workplace and relevant government agencies, such as the Regional Director of Health Services (RDHS) in Anuradhapura and the Medical Officer of Health (MOH) in Madawachchiya.

Once I established my team, I invited them to the project campaign website to pitch videos. Before the campaign began, we benefited from the monthly working group organized by TDR Global. This created a community around our crowdfunding project concept and helped expand our list of potential stakeholders. We received support from our university and student volunteers. We also interviewed patients who had leishmaniasis in the past in order to inform the video pitch. With the help of

our TDR Global mentor with expertise in communications, we drafted a campaign page. Comments and recommendations from other mentors increased the scientific rigor of the proposed study.

Applications were submitted to the institutional approval committees for both ethical (Ethical Review Committee (ERC)) and budgetary (Finance Committee) permissions. We created lists of potential backers and networks. We classified personal networks into three types: (a) friends and family; (b) collaborators; (c) alumni and others. We solicited contact information of influential people interested in our idea while preparing for our launch in order to expand our network.

Furthermore, we collected email contacts from several sources: events, social media and in-person contacts and engaged with them to promote our campaign on various online and offline media platforms.

During campaign activities

We built outreach lists, designed templates, and created an email schedule for two separate groups. One group of friends and family received emails every five days. One group of alumni and others received emails every two weeks. Our mailing list contacts actively contributed and spread the word about our campaign. Additionally, Sri Lankan embassies in Italy and Austria helped spread the crowdfunding campaign news among the Sri Lankan groups residing in these countries. Since the main goal was to keep

the campaign's momentum going, we kept sending news, trends and other pertinent updates to supporters throughout the campaign. We also sent a weekly update email on the amount donated, the number of existing supporters and the progress of our activities. Other activities such as post, remark, remind, share, like, pin in social media were also made possible by the crowdfunding platform, which was constantly monitored for timely response.

Post-campaign activities

After the campaign was over, all funders were thanked and notified on the project's development through email. Furthermore, the immediate updates on the progress were uploaded on the crowdfunding campaign page. For example, the news on the special research collaborations fostered as a result of the campaign was formalized with the signing of a Memorandum of Understanding. This news was published on the campaign's main website for reference.

Monetary support

Within the 45-day campaign period, the goal was to raise US\$ 5,650. We were thrilled to receive a lot of generous support such that we were able to exceed our funding goal. The project received 128% funding. The total funds received via the campaign platform from 93 supporters

was US\$ 7,244. The average fund pledged was US\$ 78.

Non-monetary support

We received support from TDR Global as part of the initial capacity building workshop in Geneva. We also received feedback on the written pitch and video pitch from the TDR Global and other mentors.

Several undergraduate students and media specialists graciously donated their time. Two colleagues supported translations of the campaign into German, French, and Spanish and embedded subtitles into the video. The host institution, Rajarata University, helped to create and edit the video. My research team members within and outside the university played important roles to support the project.

3. Schistosomiasis Campaign in Nigeria



Title

Community-based interventions to control urogenital schistosomiasis in Dam communities in Kano State, Nigeria - Mahmud Ali Umar



Purpose of the campaign

To finance implementation research on urogenital schistosomiasis to reduce the disease burden and interrupt transmission in rural dam communities.



Pre-campaign activities

It all began after the TDR open call for the crowdfunding challenge contest and following my selection as finalist to attend a capacity-building training workshop on crowdfunding and public engagement. Upon receipt of instructions from TDR Global to make video and written pitches, I prepared the first draft with help from two TDR Global mentors. I learned the art and science of public engagement as a sine qua non for successful crowdfunding.

After the workshop, I shared the experience with colleagues at a special faculty seminar organized on 30th January, 2020, to celebrate the first World NTD Day. A multidisciplinary research team was formed with members drawn from nine different institutions. We visited community leaders, engaged the public, and mobilized beneficiary communities. We revise the written and video pitches upon receipt of feedback from

During campaign activities

On the launch day, I sent an email message to potential backers and embarked on social media campaign with attached campaign flyer. Every 2 to 3 days, I posted a message on Facebook and WhatsApp. We conducted public lectures as part of campaign promotions. With the help of communications experts in the TDR Global community, a social media campaign card was prepared and shared via TDR LinkedIn and twitter handles.

TDR Global working group members. My team created video subtitles in the local language.

We received ethical approvals from the institution review board (IRB) and Health Research Ethics Committee of the Kano State Ministry of Health. We received permission to use TDR Global logo in crowdfunding campaign materials.

I prepared an email list of potential project backers. I uploaded campaign materials onto an online research crowdfunding platform and developed a timeline for the in-person campaign. We developed a detailed schedule and action plan for the campaign. The plan had specific strategies for reaching academic groups, traditional/village groups, political groups, public sector institutions, religious institutions, and civil society organizations.

We conducted a community radio campaign in which Rahma Radio and Freedom Radio supported us to describe the project on live radio programmes without fees. Our campaign t-shirts attracted attention during community mobilization. For example, a university student contacted the team with symptoms of Schistosomiasis and was referred to a urologist who is a member of the research team.

We paid advocacy visits to diverse stakeholders, including civil society organizations such as Kano CBO Forum and Kano Network of NGOs who helped in promoting the campaign. International professional

associations such as CORE GROUP and Global Schistosomiasis Alliance (GSA) promoted the campaign. Updates were posted on the campaign page regularly.

Post-campaign activities

As the campaign ended, we had a 'thank you' radio program and expressed our appreciation to the project backers. We used local language in communication to reach out to the target audience. We organized a project launch ceremony in partnership with the host institution. Three outstanding donors received plaques. Other project supporters received certificates of recognition. Foreign project backers received their certificates by email or WhatsApp. Crowdfunding campaign findings were presented at the Parasitology and Public Health Society of Nigeria (PPSN) 2021 Conference in Abuja.

Monetary support

The 45-day campaign period ended with a tremendous success, reaching 117% of the initial goal. The initial target was USD 9,485 and we received USD 11,122. Bulk of the

donations was generated in-person from the three robust champions, the 440-strong Congress of the Academic Staff, ASUU-KUST, Management of the host institution, and the Accountant General of the Federation, Alhaji Ahmed Idris.

Non-monetary support

We received moral and political support from all categories of stakeholders, including people from traditional, political and religious institutions, as well as family, friends and colleagues. We were overwhelmed by the support from the academic staff and the Management of KUST Wudil, the host institution, the technical support from the Ministries of Health and Environment, Kano State.

Of special note is the support from the members of our Schistosomiasis Research Team.

XIII. References

1. Mitjà O, Corbacho-Monné M, Ubals M, et al. A Cluster-Randomized Trial of Hydroxychloroquine for Prevention of Covid-19. *New England Journal of Medicine* 2020; 384(5): 417-27.
2. Kpokiri EE, Sri-Pathmanathan C, Shrestha P, et al. Public engagement and crowdfunding for health research: A global qualitative evidence synthesis and TDR pilot. *medRxiv* 2021:2021.11.08.21266070. doi: 10.1101/2021.11.08.21266070. <https://www.medrxiv.org/content/10.1101/2021.11.08.21266070v1>.
3. Finley N, Swartz TH, Cao K, Tucker JD. How to make your research jump off the page: Co-creation to broaden public engagement in medical research. *PLoS Med* 2020; 17(9): e1003246. <https://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1003246>
4. Day S, Rennie S, Luo D, Tucker JD. Open to the public: paywalls and the public rationale for open access medical research publishing. *Research Involvement and Engagement* 2020; 6(1): 8. <https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-020-0182-y>



9789240039087



9 789240 039087