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## Crowdfunding for health research: a qualitative evidence synthesis and a pilot programme

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#### Abstract

Background Many low-income and middle-income country (LMIC) researchers have disadvantages when applying for research grants. Crowdfunding may help LMIC researchers to fund their research. Crowdfunding organises large groups of people to make small contributions to support a research study. This manuscript synthesises global qualitative evidence and describes a Special Programme for Research and Training in Tropical Diseases (TDR) crowdfunding pilot for LMIC researchers. Methods Our global systematic review and qualitative evidence synthesis searched six databases for qualitative data. We used a thematic synthesis approach and assessed our findings using the GRADE-CERQual approach. Building on the review findings, we organised a crowdfunding pilot to support LMIC researchers and use crowdfunding. The pilot provided an opportunity to assess the feasibility of crowdfunding for infectious diseases of poverty research in resource-constrained settings. Results Nine studies were included in the qualitative evidence synthesis. We identified seven findings which we organised into three broad domains: public engagement strategies, correlates of crowdfunding success and risks and mitigation strategies. Our pilot data suggest that crowdfunding is feasible in diverse LMIC settings. Three researchers launched crowdfunding campaigns, met their goals and received substantial monetary (raising a total of US\$26 546 across all three campaigns) and non-monetary contributions. Two researchers are still preparing for the campaign launch due to COVID-19-related difficulties. Conclusion Public engagement provides a foundation for effective crowdfunding for health research. Our evidence synthesis and pilot data provide practical strategies for LMIC researchers to engage the public and use crowdfunding. A practical guide was created to facilitate these activities across multiple settings.


## INTRODUCTION

Crowdfunding engages large groups of people who make small contributions to support a research study. ${ }^{1}$ It provides a method for researchers to engage with the

## WHAT IS ALREADY KNOWN ON THIS TOPIC

$\Rightarrow$ Crowdfunding has been used to fund health causes, technology start-ups, creative projects, and more recently, scientific research. Although crowdfunding has been used for research funding in high-income settings, there is less evidence about its feasibility in low-income and middle-income country (LMIC) settings. In addition, previous reviews of crowdfunding have not focused on public engagement strategies that may be important for developing effective crowdfunding campaigns.

## WHAT THIS STUDY ADDS

$\Rightarrow$ Our pilot programme shows that crowdfunding is feasible option for LMIC researchers and public engagement is key for crowdfunding success as it creates opportunities for the public to contribute to and be involved with the research. The qualitative evidence synthesis suggests that early-career researchers, proof-of-concept and pilot research studies may be particularly well suited to crowdfunding.

## HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

$\Rightarrow$ There are specific risks involved with crowdfunding for health research, while we highlighted some mitigation strategies for these risks, there is need for more peer-reviewed evidence on effective strategies to address these risks and the extent to which crowdfunding can support democratisation of research.
public to spur interest and cultivate local partnerships. ${ }^{2}$ Crowdfunding provides a way for communities and stakeholders to invest in locally relevant topics and directly contribute to scientific research. Crowdfunding has been used to support research studies in many high-income countries (HICs), ${ }^{3-5}$ but is rarely used in low-income and middle-income countries (LMICs). ${ }^{6}$

LMIC researchers are often disadvantaged in applying for research grants compared with their HIC counterparts due to power asymmetries within global health. ${ }^{7}$ A telling example of this is the imbalance in authorship within high-impact global health journals across the world. ${ }^{89}$ Another example is the 'brain drain' of LMIC expertise and the disproportionate funding allocated to HIC researchers compared with their LMIC counterparts. ${ }^{10}{ }^{11}$ International donors have supported the research efforts in LMICs, ${ }^{12}{ }^{13}$ which potentially leads to donor-driven research agendas, with a disregard for local needs, knowledge and languages. ${ }^{1415}$ One way to expand LMIC-based research funding is crowdfunding, a process in which researchers engage with their communities and raise funds at the local and international level in order to conduct meaningful research. More local funding for research is one step to disrupting the unequal relationships observed within global health and may contribute to creating networks within the Global South, thereby increasing LMIC ownership. ${ }^{14}$ In addition, local researchers working in their own communities may have a greater likelihood of securing research funding relevant to addressing local priorities. Crowdfunding presents a potential opportunity to democratise, decentralise and decolonise health research, and to build health networks between like-minded researchers and their communities. There is also a need to explore the associated risks of crowdfunding health research.

We organised a TDR Global open call and pilot programme to support selected LMIC researchers with their own crowdfunding for research campaigns. TDR, the Special Programme for Research and Training in Tropical Diseases is based at the WHO and is cosponsored by the UNICEF, the United Nations Development Programme, the World Bank and WHO. TDR Global is the part of TDR focused on public engagement and supports global research efforts on infectious diseases of poverty. This manuscript synthesises global qualitative evidence on crowdfunding using a systematic review and describes a TDR pilot focused on public engagement and crowdfunding led by LMIC health researchers. The overall aim is to expand the literature by summarising the available evidence on crowdfunding for research and by assessing its feasibility in LMIC settings.

## METHODS

## A systematic review and qualitative evidence synthesis

The purpose of this review was to systematically identify and synthesise evidence on crowdfunding for health research, including barriers, facilitators and implications for policy and practice. ${ }^{16}$ We followed the Cochrane handbook for conducting systematic reviews and used the 2020 PRISMA guidance. ${ }^{171819}$

We searched PubMed, EMBASE, Web of Science, Scopus, Global Health and Google Scholar. We used the key terms [Crowdfunding or public-funded or public contribution] OR AND [Research]. We also searched
registers for grey literature including theses and dissertations, article preprints, conference proceedings, and the reference lists of relevant manuscripts. Search outputs from the databases were combined and deduplicated.

Search outputs were screened by title, then abstract and finally full text. Our inclusion criteria were limited to studies reporting crowdfunding in health research and published in English, between 1 January 2000 and 23 March 2021. The search was updated on 22 September 2021 (online supplemental appendix I). We employed a qualitative evidence synthesis which only examines qualitative data. Qualitative data can examine the social context of crowdfunding, including facilitators and barriers of crowdfunding. Second, qualitative data can be useful in understanding how crowdfunding may influence intersectional issues related to gender, early career research status, and related issues. Third, qualitative studies are important for assessing values, preferences and implementation. As a result, we included studies with primary qualitative data, on crowdfunding for research, in the English language and published in the last decade. We excluded studies with purely quantitative data, editorials, opinion pieces, practical guides and reviews. Studies on crowdfunding for other reasons other than research, published over 10 years ago or in a language other than English were also excluded. Two independent reviewers (EEEK and CS) screened studies for inclusion and disagreements were resolved through consensus-based discussion with the wider team. EEEK and CS extracted relevant data, including study objectives, participants, study setting, study design, data collection methods, qualitative themes, main study findings and where possible, correlates of crowdfunding success. We also independently assessed methodological limitations using the Critical Appraisal Skills Programme tool with a checklist for each study, including validity, relevance, adequacy, methodological limitations and risk of bias. ${ }^{20}$

We used a thematic synthesis approach ${ }^{21}$ for data analysis, which involved familiarisation with the data, coding the primary studies, developing themes and using these themes to generate further understanding and hypotheses. We used the GRADE-CERQual (Confidence in the Evidence from Reviews of Qualitative research) approach to assess confidence in each qualitative review finding, based on four key components: methodological limitations, coherence of the review finding, adequacy of the data, and relevance of the included studies to the review question. ${ }^{22-27}$ After assessing each of these components, we made an overall judgement on the confidence we had in each review finding (high, moderate, low or very low). The CERQual approach has been applied to qualitative and mixed methods systematic reviews in a number of WHO global guidelines because it provides high levels of transparency and precision. ${ }^{22}$

## The pilot programme

Building on the themes identified in the qualitative evidence synthesis, we developed a crowdfunding pilot


Figure 1 Stages of the TDR Global Pilot Programme focused on public engagement and crowdfunding led by low-income and-middle-income countries (LMICs) health researchers. (TDR is the UNICEF/UNDP/World Bank/WHO Special Programme for Research and Training in Tropical Diseases).
programme in partnership with TDR Global. The main objective of this pilot programme was to test the effectiveness of crowdfunding as a means to finance health research in LMICs. The pilot took place in three stages: an open call to solicit LMIC researchers interested in crowdfunding; a capacity building workshop; the launch of a crowdfunding campaign with mentorship and support for finalists (figure 1).

## The open call

The crowdsourcing open call was designed using the framework provided by the TDR/Social Enterpreneurship to Spur Health (SESH) /Social Inovation in Health Initaitve (SIHI) Practical Guide on Crowdsourcing in Health and Health Research. ${ }^{28}$

Our open call was conducted in five steps, including convening a steering committee, promoting community participation and engagement, receiving and judging contributions, recognising the finalists and implementing solutions. Detailed information on the process of these stages is described in online supplemental appendix II. We invited stakeholders in crowdfunding to join the steering committee. The crowdfunding call had 15 confirmed steering committee members ( 9 women and 6 men ). All members of the steering committee had LMIC experience in crowdfunding for research or public engagement. The steering committee met monthly via a 1-hour videoconference to provide guidance on the open call. The open call accepted submissions over 6 weeks. We promoted the call for submissions using infographics shared on social media channels and emails. At the end of the call, all submissions were screened for eligibility by the research team and eligible entries were sent to judges. We invited independent judges from the WHO TDR Global network to review submissions. Criteria for evaluation included compelling science, capacity for public engagement and personal connection to the infectious disease topic. Emerging finalists were provided feedback and supported with capacity building trainings to launch their crowdfunding campaign. We define a finalist submission as one that achieves a mean score of

7 or above out 10 after screening and judging process. A total of 592 people volunteered to serve as judges and 47 were selected to review submissions. We selected volunteer judges based on TDR Global membership and LMIC research experience.

## Capacity building

The finalists were recognised through a TDR announcement and supported to attend a capacity-building workshop in Geneva. The one and half-day workshop included 1:1 mentoring from TDR Global members, presentations on crowdfunding (online supplemental appendix III), and group discussions about how to enhance public engagement and crowdfunding in LMICs. After the workshop, a monthly working group composed of finalists and mentors reported on crowdfunding progress.

## Campaign launch

Three finalists launched crowdfunding campaigns. They used multiple public engagement strategies to solicit both monetary and non-monetary contributions for their research projects. At the end of their campaigns, all three finalists exceeded their target amounts and raised between US $\$ 7000$ and US $\$ 11000$.

## Patient public engagement

This study was carried out as a systematic review and pilot programme. No patients were involved. The systematic review made use of publicly available research on crowdfunding for research. Our pilot programme commenced as a crowdsourcing open call to the public soliciting LMIC researchers with interest to crowdfund for their research projects. Selected finalists in the pilot programme launched their campaigns and promoted widely for public input and contributions. A working group and end-user group, with professional and practical experience with crowdfunding for health research, were invited to comment on several drafts of this manuscript. In the final stages, a TDR Global external peer review was completed and six LMIC-based peer reviewers also provided feedback. A practical guide was developed


Figure 2 PRISMA flow diagram showing selection of studies on crowdfunding for health research. PRISMA, Preffered Reporting Items for Sytematic reviews and Meta Analysis.
by the same authors alongside this systematic review, using an adapted Delphi method to enable co-creation. It is available online, open to the public and provides practical advice on how to organise public engagement and crowdfunding for health research, using evidence from this review. ${ }^{1}$

## RESULTS

## Qualitative evidence synthesis

This qualitative evidence synthesis summarises evidence from published literature on facilitators and barriers of crowdfunding for research. Our initial electronic searches yielded 498 citations after deduplication (figure 2). We assessed articles through title screening, abstract and finally through full-text screening. After exclusions, six papers from the database search met our inclusion criteria. An additional three studies were retrieved from reference lists and a grey literature search. Of the nine included studies, seven focused on HICs and two included global data, including from LMICs. The characteristics of included studies and their main findings are provided in
online supplemental appendix IV. Seven studies reported on data from one country and two reported on data from multiple countries. Four studies were qualitative studies and five were mixed methods. Full details of the critical appraisal checklists completed for each study is available in online supplemental appendix V .

Of the nine included papers, six explored the processes and factors that were associated with successful crowdfunding campaigns (table 1). ${ }^{29-33}$ Three articles assessed the feasibility of conducting crowdfunding for health and/or scientific research. ${ }^{34-36}$ We identified seven findings which we organised into three broad domains: public engagement strategies, correlates of crowdfunding success, and risks and mitigation strategies. Of the seven findings, five were graded as moderate confidence and two were graded as low confidence using the GRADECERQual approach (table 2).

## Public engagement strategies

Strong public engagement (eg, networking and disseminating appealing, clear, and locally relevant information)
Table 1 Summary of included studies and quality assessment

|  |  |  |  |  |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |
|  | Author | Study aim | Method <br> QUAL | or |

Primary data-from a creator/organiser; Secondary data-analysis of multiple campaigns (interpretation of primary data). MM, Mixed methods; QUAL, Qualitative study.
Table 2 Evidence profile and assessment of confidence in the review findings as per GRADE-CERQual methodology

|  |  | Review finding | Studies contributing to the finding | Methodological limitations | Coherence | Adequacy | Relevance | CERQual assessment of confidence in the evidence | Explanation of CERQual assessment |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| 1 |  | Strong public engagement (eg, networking and disseminating appealing, clear, and locally relevant information) facilitated crowdfunding for research. | $\begin{aligned} & 2,3,5,6,7 \\ & 8,9 \end{aligned}$ | Moderate methodological limitations due to limited reflexivity, lack of transparency on recruitment strategy, and unclear ethical considerations Two studies (5 and 6) lacked formal qualitative analysis | Minor concerns about coherence | Minor concerns regarding adequacy due to contributions from seven studies with moderately thick data. | Minor concerns about relevance, although six studies presented data from high income countries. Only one study (9) presents globally acquired data | Moderate confidence | Minor concerns over coherence, adequacy, and relevance. Moderate methodological limitations. |
|  |  | Crowdfunding expanded bidirectional communication between researchers and the public. It opened a channel between researchers and the public, and increased the public's trust, awareness, and understanding of science. | 5, 6, 7, 9 | Serious methodological limitations (two studies with no or minor concerns $(7,9)$ and two studies $(5,6)$ with severe concerns following incomplete analysis on a very small sample) | Moderate concerns about coherence due to study findings based on insufficiently analysed data | Serious concerns about adequacy due to weak and at times incomplete analysis presented in 2 out of 4 studies contributing to this review finding. | Minor concerns about relevance, with three studies mainly focused on crowdfunding and research success, one study focused on selected platforms from high income countries alone | Low confidence | Due to minor concerns about relevance, Moderate concerns about coherence and Serious concerns about adequacy and Serious methodological limitations |
|  |  | Correlates of funding success included lower funding targets, researcher endorsements, the offer of rewards, testimonials, and input from known NGOs. Projects were also more successful if they were hosted on scientific crowdfunding platforms. | 2, 7, 9 | Minor methodological limitations, robust qualitative analysis presented from all three studies. Strong methodology presented with four conceptual frameworks in one study (9) | Moderate concerns about coherence, because one study finding (9) contradicts another (2) | Moderate concerns regarding adequacy The findings from two studies $(2,9)$ are limited to one platform | Minor concerns about relevance All studies focused on success indicators for crowdfunding | Moderate confidence | Minor concerns for methodological limitations and relevance but moderate concerns for coherence and adequacy |
|  |  | Students, early career researchers, and people using innovative methods were more likely to meet their crowdfunding goals and benefit more from the process. | $3,4,7,9$ | Moderate methodological limitations due to lack of reflexivity $(4,7,9)$; unclear recruitment strategy and limited data analysis (3) | Minor concerns about coherence | Moderate concerns about adequacy Due to three contributing studies with thick data (4, 7 , 9) and one study with moderately thick data | Moderate concerns about relevance All studies are relevant, but three contributing studies are only focused on highincome contexts | Moderate confidence | Minor concerns regarding coherence. Moderate concerns regarding adequacy, relevance and methodological limitations. |

Table 2 Continued

|  |  | Review finding | Studies contributing to the finding | Methodological limitations | Coherence | Adequacy | Relevance | CERQual assessment of confidence in the evidence | Explanation of CERQual assessment |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  | Early-stage, proof-of -concept, pilot research and other smaller scale research projects were more suited to crowdfunding. | $\begin{aligned} & 1,2,3,4,5, \\ & 6,7 \end{aligned}$ | Moderate methodological limitations (two studies with no concerns $(4,7)$ one study with minor concerns, 2 studies with moderate concerns due to small sample size and one study with severe concerns following incomplete analysis on a very small sample) | Minor concerns about coherence | Moderate concerns about adequacy due to low sample size from two studies $(1,7)$ with moderately thick data from four studies (1,2,3,4) and thin data from one study | Minor concerns about relevance as all study mainly focus on crowdfunding for health research and related medical disease. Findings mainly are from high income settings with relevance in other settings. | Moderate confidence | Moderate level of confidence due to minor concerns about relevance and coherence and moderate concerns about adequacy and moderate methodological limitations |
|  | $\pi$ | There are concerns regarding the ethics and risks of crowdfunding. Evidence suggests there was a lack of standardised peer review to ensure projects are ethically sound, valuable and of high scientific quality | 2, 3, 6, 7, 9 | Moderate methodological limitations Severe concerns for one study (6) due to a lack of formal qualitative analysis. Moderate or minor concerns for the other studies due to recruitment strategy ambiguity and limited reflexivity $(2,3,7,9)$ | Minor concerns about coherence | Moderate concerns about adequacy Due to three contributing studies with moderately thick data (2, 3, 7, 9) and one study with thin data (6) | Moderate concerns about relevance due to evidence from limited contexts, with data mainly from high-income settings. | Moderate confidence | Minor concerns regarding coherence. Moderate concerns regarding adequacy, relevance, and methodological limitations. |
|  |  | The risks associated with crowdfunding may be mitigated by involving expert reviewers to assess quality, developing partnerships with NonGovernmental Organisations (NGOs), universities and other institutions and by seeking mentorship from senior researchers | 3, 4, 6, 7 | Moderate methodological limitations due to limited reflexivity and a lack of formal data analysis in one study (6) | Moderate concerns about coherence due to gaps in the data that could specifically back this finding | Moderate concerns about adequacy three contributing studies with moderately thick data | Moderate concerns about relevance due to data coming only from high-income settings. | Low confidence | Moderate concerns regarding methodology, coherence, adequacy, and relevance. |

facilitated crowdfunding for research (Moderate confidence). ${ }^{2} 29-3336$

We define public engagement in research as two-way communication between the researcher and the public for mutual benefit. Evidence showed that networking skills and the ability to share a campaign among personal, professional and social media networks were strongly associated with achieving crowdfunding campaign goals. Using multiple communication channels, including social media, blogs, direct contact, email, newspaper, community radio, in-person events and conferences was also recommended. Using simple messages delivered by image or video increased donations: four studies suggested that campaigns with videos were more likely to succeed and were preferred by potential backers. ${ }^{31-33} 36$ They also found that keeping the audience updated through regular communication during and after the campaign led to more pledges and higher odds of success. ${ }^{3132}$ Four studies found that researchers who partnered with nongovernmental organisations, universities or foundations enhanced their public engagement achievements. ${ }^{29-31 ~ 34}$

Crowdfunding expanded bidirectional communication between researchers and the public. This channel between researchers and the public increased the public's trust, awareness, and understanding of science (low confidence) ${ }^{231-33}$

One study found that feedback mechanisms, particularly two-way feedback between the backers and the researcher, significantly increased crowdfunding success. ${ }^{33}$ Evidence showed that crowdfunding can also help to bridge the gap between society and science by promoting public understanding of science through accessible resources. ${ }^{2} 31-33$

## Correlates of crowdfunding success

Correlates of funding success included lower funding targets, researcher endorsements, the offer of rewards to backers, and testimonials and input from known NGOs. Projects were also more successful if they were hosted on scientific crowdfunding platforms (Moderate confidence). ${ }^{30} 3233$

In addition to public engagement and communication strategies, certain factors were associated with crowdfunding success. One study found that campaigns hosted on specialised scientific crowdfunding platforms were more likely to reach their goals compared with campaigns on general interest crowdfunding platforms. ${ }^{30}$ Projects that offered rewards (eg, small gifts to backers) had higher odds of achieving their goals. ${ }^{32}$ The evidence on researcher endorsements is mixed. One study found that researcher endorsements by other professionals increased funding success, ${ }^{32}$ but another found that research quality signals (highest academic title, scientific awards and the complexity and length of project description) had no effect on funding success. ${ }^{33}$ Similarly, endorsements and the sponsorship of platforms by established journals were not correlated with funding success.

In a survey of stated preferences, one study found that researcher reputation is important to backers. ${ }^{29}$

Students, early career researchers and people using innovative methods were more likely to meet their crowdfunding goals and benefit from the process. (Moderate confidence ${ }^{32-3436}$

Four studies found that students, early career researchers, and people with innovative studies were more likely to meet their campaign goals and benefit from the process. ${ }^{32-3436}$ Early career researchers were defined as people within ten years of a terminal degree and it was found they had higher rates of achieving financial crowdfunding goals. Although established researchers have larger research networks, crowdfunding engages broader audiences, therefore, traditional markers of quality, such as prior publications and researcher reputation, may not be so important. Three studies found that project risk was not associated with lower odds of success. ${ }^{232} 33$ However, one study found that some donors remained risk-averse and that innovative projects were modestly less successful. ${ }^{30}$

Early-stage, proof-of -concept, pilot research and other smaller scale research projects were more suited to crowdfunding. (Moderate confidence) ${ }^{2} 30-3234-36$

Seven studies showed that crowdfunding may be an effective option to rapidly raise funds for research projects. ${ }^{2}{ }^{30-32}{ }^{34-36}$ Studies suggested that crowdfunding may be especially useful for pilot, phase one clinical trials, or early-stage proof-of-concept research because campaigns with smaller targets were usually more successful. ${ }^{29} 35$ Crowdfunding could complement or extend an existing research project. Alternatively, crowdfunding could support pilot studies, in sight of later applying to larger funding grants. ${ }^{36}$ One study on crowdfunding for clinical trials found that $95 \%$ of campaigns used a flexible model where researchers kept all the funds raised. ${ }^{35}$ These flexible models enabled researchers to get started on projects regardless of whether they reached their target, in contrast to all-or-nothing models, making crowdfunding a useful source of 'seed money'. Two studies found crowdfunding is an effective way to support drug development on cancer, rare diseases, neglected tropical diseases and infectious diseases of poverty. ${ }^{31} 34$

## Risks and mitigation strategies

There were concerns regarding the ethics and potential risks of crowdfunding. Evidence suggested there was a lack of standardised peer review to ensure projects are ethically sound, valuable and of high scientific quality. (Moderate confidence) ${ }^{230323336}$

Five studies found that crowdfunding for scientific research was based on the public's judgement and may thus promote research that is low-value, ethically unsound or not methodologically rigorous. ${ }^{2} 30323336$ Additional limitations of crowdfunding include the inability to monitor research funding allocation postcampaign and to sanction fraud and falsification.

Table 3 Details of finalist projects for public engagement and crowdfunding in the TDR Global open call and pilot programme

| S/N | Countrydisease | Project aim | Gender | Public engagement strategies in preparation for campaign launch | Amount asked/ amount raised | Number of backers/ mean donation | Non-monetary support |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| 1 | Sri Lanka- <br> Leishmaniasis | To facilitate sand fly vector and leishmaniasis disease control via instructions and improving access | F | Video pitch, students and social media, diaspora citizens, Emails | $\begin{aligned} & \text { US\$5650/ } \\ & \text { US\$7244 } \end{aligned}$ | 89 backers/US\$81 | Video editing support from university, translation support, communications help from students |
| 2 | ThailandZika Virus | To neutralise and block Zika transmission from mother to child during pregnancy | M | Video pitch, social media posts, alumni networks, Spanish translation | $\begin{aligned} & \text { US\$8000/ } \\ & \text { US\$8180 } \end{aligned}$ | 102 backers/US\$82 | Video design and editing support from research institute |
| 3 | NigeriaUrogenital Schistosomiasis | To implement effective strategies to reduce the urogenital schistosomiasis disease in dam-site communities | M | Video pitch, radio announcement, local presentations, community leaders, citizens in diaspora, clean water foundations | US\$9485/US\$11 $122$ | 100 backers/ US\$111.2 | Communications support from the university and technical support from public sector groups |
| 4 | GuatemalaCutaneous leishmaniasis | To reduce time for diagnosis and treatment of cutaneous leishmaniasis using a community operated mobile clinic with an artificial intelligence system | F | Video pitch, personal stories, promotion with students, social media posts |  |  | Preparing for crowdfunding campaign* |
| 5 | MozambiqueTuberculosis | Towards tuberculosis elimination through shorter preventive therapy, employing community health workers to increase patient access and treatment uptake | M | Video pitch and social media posts |  |  | Preparing for crowdfunding campaign* |

The risks associated with crowdfunding may be mitigated by involving expert reviewers to assess quality, developing partnerships with NGOs, universities, and other institutions, and seeking mentorship from senior researchers. (low confidence) ${ }^{2323436}$
Two studies found an internal peer review system could be a solution to promoting high-quality research related to crowdfunding. ${ }^{32}{ }^{36}$ Some platforms required approval from ethical committees prior to launching their campaign, but these requirements varied. ${ }^{32}$ Seeking mentorship and partnering with NGOs specialised in marketing and fundraising helped researchers. ${ }^{34}$ They could facilitate efficient research administration and facilitate payment collection.

## Pilot programme

The open call received 121 unique submissions from researchers based in 37 LMICs. The judging process was conducted in three phases. In the first phase, all 121
entries were screened for eligibility using predefined criteria, including a clear description of the scientific question and hypothesis, significance of the project and relevance to the public. Submissions were not screened based on their location or research project topic. This initial screening yielded 66 eligible entries. All eligible entries were then reviewed by judges and assigned scores. Entries that achieved a mean score of 7 and above out of 10 and were recognised as finalists. With resources available, the pilot programme was initially designed to support only three finalists' submission in their campaign launch but after screening and judging following a high number of high quality entries, five finalist submissions were selected to receive support. The five finalists were from Guatemala, Mozambique, Nigeria, Sri Lanka and Thailand (table 3). All described social innovations in health and focused on infectious diseases of poverty.

## Box 1 Practical recommendations for implementing crowdfunding for research*

1. Public engagement is an important component for conducting a successful crowdfunding for research campaign.
2. Bidirectional communication may increase the number of crowdfunding donations and enhance the public's trust and understanding of science.
3. Young scholars and early-career researchers may consider crowdfunding for their research.
4. Smaller crowdfunded grants can top up existing research funding or fund early-stage research that can then be used to apply to public research grants.
5. Partnerships with experts can provide some feedback and improve the rigour of research prior to launching a crowdfunding campaign.
6. Seeking formal organisational approvals and ethical committee reviews can increase the likelihood of success.
7. To increase donations, campaigns should include quality signals, such as endorsements and testimonials, offer rewards, partner with known NGOs and aim for a realistic funding target.
*A practical guide was developed alongside this review. Researchers interested in strategies and tools to optimise their crowdfunding campaigns can access this guide. https://crowdfundinghealth.org/.

All five finalists used the tools of public engagement to develop campaign videos for their research project and benefitted from substantial non-monetary support (table 3). In-kind contributions included assistance with developing and editing short videos from their universities, student support on social media, and scientific mentorship from TDR Global members. Among the five finalists, three had launched their crowdfunding campaigns as at the time of writing this report. Two finalists had faced some delays due to administrative challenges and personal circumstances compounded by the COVID-19-related closures. All three that launched employed intensive public engagement strategies and used existing networks to drive and publicise their campaign. At the end of the campaign promotions, they all exceeded their original financial crowdfunding goals (table 3).

The pilot programme identified some practical recommendations for implementing a crowdfunding campaign (box 1). It also identified potential risks and risk mitigation strategies (online supplemental appendix VI). Potential risks of crowdfunding included fraud and deception, misinformation, unfair allocation of funds and lack of public interest in the project. Strategies to mitigate these risks included obtaining ethical approvals and support from local experts, clear communication throughout the campaign, sharing project results using open-access tools, transparent engagement through videos and personal stories, and partnerships with universities or community-based organisations.

## DISCUSSION

This paper expands the literature by summarising the qualitative evidence available on crowdfunding for health
research and by assessing its feasibility in LMIC settings. Most of the evidence collected in our review has come from HIC settings. ${ }^{35} 37-39$ The pilot programme complements this by demonstrating that LMIC researchers can benefit from the monetary and non-monetary support that crowdfunding provides. Crowdfunding could also be a powerful tool to decentralise and democratise research funding in resource-constrained settings.

Both the systematic review and pilot programme highlight that public engagement is essential for crowdfunding. Previous studies have shown that public engagement generates interest, which in turn leads to backers offering to help with projects and providing feedback. ${ }^{40}$ Public engagement skills may help to translate scientific concepts into more easily understood messages. ${ }^{40}$ Active engagement with the public during the campaign across a wide range of mediums (lab notes, email updates, online webinars) can increase fundraising success. ${ }^{32}$ Although all three pilot programme finalists who launched their campaign had limited social media experience, they were successful in developing effective digital engagement strategies. These three finalists used videos as part of their campaigns-this may have enhanced the public's trust in their projects, thus contributing to their crowdfunding success, consistent with evidence on the importance of videos in science communication. ${ }^{41}$ The finalists received training on storytelling, and they found that using personal stories from affected community members made their video pitches more meaningful and inclusive. This is consistent with fundraising literature demonstrating that personal stories can be a useful tool to seek funding from donors for non-profit causes. ${ }^{42} 43$

Our systematic review shows that early-stage investigators and research studies with innovative methods were likely to reach crowdfunding goals. The public may place less emphasis on previous research experience compared with other research grant funding application processes. ${ }^{30}{ }^{33}$ Therefore, campaigns with a broad engaged audience and efficient public engagement strategies alone can be successful in funding innovative research. In addition, we found that crowdfunding is useful for early-stage research and can then be used as preliminary data for larger grants.

Our pilot programme data demonstrate that crowdfunding is feasible in diverse LMIC settings. Evidence suggests there are barriers to seeking traditional research funding for many LMIC researchers, including fewer institutional research resources, less experience with research grants and racism in science. ${ }^{44} 45$ One previously mentioned example is authorship and the fact that LMIC researchers who have worked in international partnerships are less likely to be first or corresponding authors. ${ }^{46}$ This likely disadvantages LMIC researchers when applying for grants as authorship in publications is often a marker of researcher reputation and signals productivity. ${ }^{47}$ Crowdfunding may be a useful tool for LMIC researchers to directly obtain support for research with less reliance on external
donors or HIC researchers. It can also be argued that because crowdfunded research is often more grassroots and community based, it may be more ethical and have a more enduring positive impact. ${ }^{48}$

Our data from the pilot programme identified strategies to mitigate ethical issues associated with crowdfunding. We found mentorship from local experts could alleviate some of the concerns raised about the limited peer review of crowdfunded health research projects. During the pilot, our TDR Global team was involved in building local partnerships and mentorship opportunities to mitigate this risk. Additional risk mitigation strategies include obtaining ethical committee review approval prior to launch, ensuring transparency throughout the campaign, and the use of open-access tools to disseminate findings. Finalists were also encouraged to build south-south partnerships and seek support from colleagues who were not part of the research team. This finding is consistent with other literature showing that south-south collaboration can improve research quality. ${ }^{49}$

Our study has several limitations. First, we identified only few studies with qualitative data for inclusion, however, further qualitative research looking at crowdfunding metrics would greatly enrich the literature on this topic. Second, the studies identified from the qualitative evidence synthesis were disproportionately from HICs and only included articles in the English language. There were however data from some LMICs and the pilot programme did provide detailed complementary information on the feasibility of crowdfunding in LMIC settings. Finally, previous studies have shown that charitable crowdfunding is greatly influenced by social capital, and that this can increase inequities. ${ }^{50}$ However, social capital can be built through effective public engagement before and during campaign launch. ${ }^{51}$ In addition, crowdfunding for health research benefits a wider community of people and may not be subject to the same dynamics as charitable crowdfunding for individuals (ie, medical bills) and private projects. Further research is needed to assess this particular phenomenon as crowdfunding for health research expands.

This research has implications for research and policy. Our pilot demonstrates that crowdfunding is feasible to support infectious disease research in LMICs. Public engagement can build horizontal local partnerships, contributing to empowering local funding sources for global health research. From a policy perspective, crowdfunding has not been widely used to support research studies and few platforms focus on scientific and health research, with even fewer crowdfunding platforms based in LMICs as opposed to HICs. In addition, because previous research suggests that charitable crowdfunding may exacerbate social inequalities, more research is needed to analyse this phenomenon in the setting of crowdfunding for scientific research. Global health institutions and
universities should help LMIC researchers to consider crowdfunding their research. ${ }^{234}$ Our WHO-TDR practical guide provides additional guidance ${ }^{1}$ and helps to expand the uptake of crowdfunding for research. While our initial pilot was organised and supported by TDR Global, further institutional support will be essential for building capacity related to public engagement and crowdfunding.

Our data demonstrate that crowdfunding is an alternative option to support research in LMIC settings and it may be particularly well-suited to early-stage work led by early-career researchers. Crowdfunding could be a useful incremental step to decentralise research funding and reorient some of the core underlying principles that underpin global health funding. However, there is a need to build on this finding by testing the approach in multi-site studies and exploring strategies to mitigate some of the risks to build trust and confidence.

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## REFERENCES

1 WHO/TDR/SESH/SIHI. Public engagement and crowdfunding in health research: a practical guide. Geneva, Switzerland: WHO, 2021.
2 Byrnes JEK, Ranganathan J, Walker BLE, et al. To crowdfund research, scientists must build an audience for their work. PLoS One 2014;9:e110329.
3 Siva N. Crowdfunding for medical research picks up PACE. Lancet 2014;384:1085-6.
4 Renwick MJ, Mossialos E. Crowdfunding our health: economic risks and benefits. Soc Sci Med 2017;191:48-56.
5 Snyder J, Crooks VA, Mathers A, et al. Appealing to the crowd: ethical justifications in Canadian medical crowdfunding campaigns. J Med Ethics 2017;43:364-7.
6 Akwaowo CD, Umoh IO, Udoh AI. Crowdfunding for cancer: successes and challenges of a female physician's organization in Nigeria. Af J Health Econom 2020;9:46-52.
7 Munim ZH, Shneor R, Adewumi OM. Determinants of crowdfunding intention in a developing economy: ex-ante evidence from Bangladesh. Int J Emerg Market 2020.
8 Nafade V, Sen P, Pai M. Global health journals need to address equity, diversity and inclusion. BMJ Glob Health 2019;4:e002018.
9 Hedt-Gauthier BL, Jeufack HM, Neufeld NH, et al. Stuck in the middle: a systematic review of authorship in collaborative health research in Africa, 2014-2016. BMJ Glob Health 2019;4:e001853.
10 Bekele A, Chu K, D'Ambruoso L, et al. Global health research funding applications: brain drain under another name? Lancet Glob Health 2022;10:e22-3.

11 Adam T, Akuffo H, Carter JG, et al. World RePORT: a database for mapping biomedical research funding. Lancet Glob Health 2020;8:e27-9.
12 Collins F, Beaudet A, Draghia-Akli R, et al. A database on global health research in Africa. Lancet Glob Health 2013;1:e64-5.
13 Siegfried N, Clarke M, Volmink J, et al. African HIV/AIDS trials are more likely to report adequate allocation concealment and random generation than North American trials. PLoS One 2008;3:e3491.
14 Abimbola S, Asthana S, Montenegro C, et al. Addressing power asymmetries in global health: imperatives in the wake of the COVID-19 pandemic. PLoS Med 2021;18:e1003604.
15 Cash-Gibson L, Rojas-Gualdrón DF, Pericàs JM, et al. Inequalities in global health inequalities research: a 50-year bibliometric analysis (1966-2015). PLoS One 2018;13:e0191901.
16 Munn Z, Peters MDJ, Stern C, et al. Systematic review or scoping review? Guidance for authors when choosing between a systematic or scoping review approach. BMC Med Res Methodol 2018;18:1-7.
17 Green S, Higgins J. Cochrane handbook for conducting systematic reviews. Cochrane Collaboration 2011.
18 Page MJ, McKenzie JE, Bossuyt PM. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372.
19 Kpokiri EE, PhD S-P, Shrestha C. Public engagement and crowdfunding for research: a systematic review, qualitativee evidence synthesis and TDR pilot. OSF Registry 2021.
20 Casp U. Critical appraisal skills programme (CASP). Qualit Res Checklist 2017;31:449.
21 Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews (ESRC national centre for research methods working paper series number 10/07) 2008.
22 Lewin S, Glenton C, Munthe-Kaas H, et al. Using qualitative evidence in decision making for health and social interventions: an approach to assess confidence in findings from qualitative evidence syntheses (GRADE-CERQual). PLoS Med 2015;12:e1001895.
23 Lewin S, Bohren M, Rashidian A, et al. Applying GRADE-CERQual to qualitative evidence synthesis findings - paper 2: how to make an overall CERQual assessment of confidence and create a summary of qualitative findings table. Implement Sci 2018;13:11-23.
24 Munthe-Kaas H, Bohren MA, Glenton C, et al. Applying GRADECERQual to qualitative evidence synthesis findings - paper 3: how to assess methodological limitations. Implement Sci 2018;13:25-32.
25 Glenton C, Carlsen B, Lewin S, et al. Applying GRADE-CERQual to qualitative evidence synthesis findings-paper 5: how to assess adequacy of data. Implement Sci 2018;13:43-50.
26 Noyes J, Booth A, Lewin S, et al. Applying GRADE-CERQual to qualitative evidence synthesis findings-paper 6: how to assess relevance of the data. Implement Sci 2018;13:51-61.
27 Colvin CJ, Garside R, Wainwright M, et al. Applying GRADECERQual to qualitative evidence synthesis findings-paper 4: how to assess coherence. Implement Sci 2018;13:33-41.
28 World Health Organization, UNICEF. Crowdsourcing in health and health research: a practical guide. World Health Organization, 2018.
29 Dragojlovic N, Lynd LD. What will the crowd fund? Preferences of prospective donors for drug development fundraising campaigns. Drug Discov Today 2016;21:1863-8.
30 Aleksina A, Akulenka S, Lublóy Ágnes. Success factors of crowdfunding campaigns in medical research: perceptions and reality. Drug Discov Today 2019;24:1413-20.
31 Ortiz RA, Witte S, Gouw A, et al. Engaging a community for rare genetic disease: best practices and education from individual crowdfunding campaigns. Interact J Med Res 2018;7:e3.
32 Sauermann H, Franzoni C, Shafi K. Crowdfunding scientific research: descriptive insights and correlates of funding success. PLoS One 2019;14:e0208384.
33 Schäfer MS, Metag J, Feustle J, et al. Selling science 2.0: what scientific projects receive crowdfunding online? Public Underst Sci 2018;27:496-514.
34 Dragojlovic N, Lynd LD. Crowdfunding drug development: the state of play in oncology and rare diseases. Drug Discov Today 2014;19:1775-80.
35 Sharma A, Khan JS, Khan J, et al. Is crowdfunding a viable source of clinical trial research funding? Lancet 2015;386:338.
36 Krittanawong C, Zhang HJ, Aydar M, et al. Crowdfunding for cardiovascular research. Int J Cardiol 2018;250:268-9.
37 Schucht P, Roccaro-Waldmeyer DM, Murek M, et al. Exploring novel funding strategies for innovative medical research: the HORAO crowdfunding campaign. J Med Internet Res 2020;22:e19715.
38 Oonyu LM. Guide for Leveraging crowdfunding to bridge scientific research resource gaps in developing countries: descriptive insights, prospects and challenges from selected African countries 2020.

39 Jin P. Medical crowdfunding in China: empirics and ethics. J Med Ethics 2019;45:538-44.
40 Makris GC. Crowdfunding: from startup businesses to startup science. BMJ 2015;350:h18.
41 Finkler W, Leon B. The power of storytelling and video: a visual rhetoric for science communication. J Sci Commun 2019;18:A02.
42 Fumagalli DC, Gouw AM. Focus: personalized medicine: crowdfunding for personalized medicine research. Yale J Biol Med 2015;88:413.
43 Zhou H, Ye S, Legitimacy YS. Legitimacy, Worthiness, and social network: an empirical study of the key factors influencing crowdfunding outcomes for nonprofit projects. Voluntas 2019;30:849-64.
44 Khan M, Abimbola S, Aloudat T, et al. Decolonising global health in 2021: a roadmap to move from rhetoric to reform. BMJ Glob Health 2021;6:e005604.
45 Besson EK. Confronting whiteness and decolonising global health institutions. Lancet 2021;397:2328-9.

46 Abimbola S. The foreign gaze: authorship in academic global health. BMJ Glob Health 2019;4:e002068.
47 Lawrence DS, Hirsch LA. Decolonising global health: transnational research partnerships under the spotlight. Int Health 2020;12:518-23.
48 Perry JE. The people's NIH-ethical and legal concerns in crowdfunded biomedical research. Notre Dame JL Ethics \& Pub Pol'y 2015;29:453.
49 Omaswa F, Kiguli-Malwadde E, Donkor P, et al. The medical education partnership initiative (MEPI): innovations and lessons for health professions training and research in Africa. Ann Glob Health 2018;84:160.
50 Igra M, Kenworthy N, Luchsinger C, et al. Crowdfunding as a response to COVID-19: increasing inequities at a time of crisis. Soc Sci Med 2021;282:114105.
51 Cai W, Polzin F, Stam E. Crowdfunding and social capital: a systematic review using a dynamic perspective. Technol Forecast Soc Change 2021;162:120412.

## Supplemental Files crowdfunding for health research

Appendix I: Updated Search algorithm
Appendix II: Details of the open call
Appendix III: Specific topics delivered to finalist at the capacity building workshop
Appendix IV: Characteristics of included studies
Appendix V: CASP checklists for all included studies
Appendix VI: Risks in crowdfunding and our mitigation strategies from the TDR pilot

## Appendix I: Updated Search algorithm

Databases:
PubMed, EMBASE, Web of Science, Scopus, Global Health and Google Scholar.

## Keywords:

| "crowdfunding" OR "crowdfund" |
| :--- |
| AND |
| "research" |


| Keyword | Search details | Results |
| :--- | :--- | :--- |
| PubMed |  | "crowdfunding"[All Fields] |
| Crowdfunding | "Research"[MeSH Terms] | 236 |
| Research | (crowdfunding)AND <br> (research) | "crowdfunding"[All Fields] AND ("research personnel"[MeSH <br> Terms] OR ("research"[All Fields] AND "personnel"[All Fields]) <br> OR "research personnel"[All Fields] OR "researcher"[All Fields] |
| OR "researchers"[All Fields] OR "research"[MeSH Terms] OR <br> "research"[All Fields] OR "research s"[All Fields] OR <br> "researchable"[All Fields] OR "researche"[All Fields] OR <br> "researched"[All Fields] OR "researcher s"[All Fields] OR <br> "researches"[All Fields] OR "researching"[All Fields] OR <br> "researchs"[All Fields]) | 157 |  |

EMBASE, Web of Science, Scopus, Global Health and Google Scholar

| Crowdfund* | Crowdfund*.mp. [mp=ti, ab, hw, tc, id, ot, tm, mf, tn, dm, dv, kf, <br> fx, dq, bt, cc, nm, ox, px, rx, an, ui, sy, pt] | 729 |
| :--- | :--- | :--- |
| Research | Research.mp. $[\mathrm{mp}=\mathrm{ti}, \mathrm{ab}, \mathrm{hw}, \mathrm{tc}, \mathrm{id}, \mathrm{ot}, \mathrm{tm}, \mathrm{mf}, \mathrm{tn}, \mathrm{dm}, \mathrm{dv}, \mathrm{kf}, \mathrm{fx}$, <br> dq, bt, cc, nm, ox, px, rx, an, ui, sy, pt] | $15,815,014$ |
| Crowdfund* AND <br> Research | 1 and 2 | 368 |

## Appendix II: In depth details of the open call

## The crowdfunding open call

In partnership with the UNICEF/UNDP/World Bank/WHO Special Programme for Research and Training in Tropical Diseases (TDR), SESH (Social Entrepreneurship to Spur Health) and the Social Innovation in Health (SIHI), the London School of Hygiene and Tropical Medicine organized the open call for low-and-middle-income countries (LMIC) infectious disease research. The contest was officially launched on May $15^{\text {th }}, 2019$ and the deadline for submissions was June 30 th , 2019. An open call for submissions was developed and the steering committee reviewed and finalized the details. A simple website was created for promotion and to host information on the open call including the purpose, categories of participation, eligibility, timelines, steering committee members, and partners. A submission portal was also available on the website. Participant eligibility included anyone who is a citizen of an LMIC and locally resident in the LMIC where the project is to be implemented.

## Organizing a steering committee

The crowdfunding call had 15 confirmed steering committee members from different countries with, 9 females and 6 males. Of this number, 7 had crowdfunding and/or public engagement research experience in LMICs. The purpose of the steering committee was to provide guidance feedback throughout the duration of the open call. The committee met monthly through 60-minute teleconference meeting. During meetings, issues with regards to the contest design, organization, and implementation and subsequent progress were discussed.

## Engaging the community to contribute

The call for submissions opened on May 16 ${ }^{\text {th }}$, 2019. Promotional information was disseminated using infographics on social media channels, blog posts, email, and personal contacts. Emails were sent out to partner networks, TDR, SESH, SIHI and to other relevant entities and individuals. Hard copies fliers were printed out with the details on the open call and distributed in relevant places including academic institutions. Promotional activities for entries continued until the deadline for submissions (30 th June 2019). At the end of the call, we received a total of 121 unique submissions from 37 different countries.

## Receiving and evaluating contributions

A digital submission form was made using Qualtrics Survey Software and embedded in the contest website. During the call duration, submissions were received via the Qualtrics submission portal on the website and some entries were received through the contest email address. Through the submission form, in addition to the entries, we collected the following sociodemographic details including participants: name, email institution, and country.

The evaluation process was conducted in three stages which includes first screening for eligibility, secondly reviewing eligible entries and assigning a score between 1-10. The third stage of evaluation was in-depth review with feedback and comments provided for revisions. At the deadline, all submissions were screened for eligibility using the format for entries posted on the website which includes a 1200-word summary of the project proposed highlighting (1) scientific question and hypothesis; (2) significance of the project; (3) relevance to the public; (4) personal motivation for research and personal connection to the disease and geographic location; (5) areas mentorship will be needed.

After screening, the eligible entries were transferred to independent judges for phase 2 judging. A call for volunteer judges to review the submissions was sent out and our call for volunteer judges received 592 responses and 47 were selected to review submissions.
During phase judging, each submission was awarded an individual score between 1 and 10 (where 1 is the weakest and 10 is strongest submission). The scores assigned were based on predetermined criteria set out in a judging rubric. Criteria for evaluation include compelling science, capacity for public engagement, and personal connection to the infectious disease topic. At the end of the second stage judging, five submissions achieved a mean score of 7 and above and emerged as finalists. These 5 finalists in a third stage of judging received detailed feedback on their written pitches.

## Recognizing finalists

The five finalists' entries were from Guatemala, Mozambique, Nigeria, Sri Lanka and Thailand and included 3 males and 2 females. All the five finalists were announced through the WHO TDR News and other organizing partner networks and were supported to attend a 1.5 day capacity building workshop organized for them in Geneva, Switzerland. During the workshop, the finalists were assigned individual mentors and were given time slots to present their project pitches and received group feedback. They also received training on public engagement and storytelling, effective project planning and evaluation, writing a proposal, crowdsourcing, implementation research, and choosing a platform.

## Sharing and implementing solutions

During the capacity building workshop, finalists were the given opportunity to share their research projects and receive feedback from the group. After which a working group including some of the steering committee members and the finalists was set up to meet monthly and further hone the written and video pitches in preparation for campaign launch.

Appendix III: Specific topics delivered to finalist at the capacity building workshop

| Topics | Key messages |
| :--- | :--- |
| Crowdfunding and Ethics | Accountability in crowdfunding <br> Before research: start ethical approval process <br> During research: giving back to backers, keep updated <br> After research: open access materials <br> Other ethical considerations: seek endorsements |
| Storytelling for public <br> Engagement | Capture attention <br> Be memorable <br> Inspire action |
| Study design in <br> implementation research | Identifying implementation research problems/questions <br> Socio-cultural and economic factors <br> Phase 1: identify possible implementation strategies <br> Phase 2: develop implementation strategies <br> Phase 3: testing effectiveness of implementation strategies <br> Phase 4: scaling up |
| Launching a crowdfunding <br> campaign | Expand the network of people engaged with your <br> research. <br> Communicate your process and results to a broader -and <br> new audience. <br> Get funding! |
| Effective Project Planning | Proposal: scientific merit, social value, well planned <br> project. <br> Audience should have all the elements to understand the <br> Project to be financed <br> Different ways to cross the message to the audience. <br> One way: flow diagram showing the Project development <br> plan <br> Ideally the diagram should be auto explicit, visual and <br> useful for general audience |
| Crowdsourcing | Why crowdsourcing to improve health? (1) Innovation, <br> (2) Engages new groups and networks, (3) People- <br> centered <br> Types: challenge contests, hackathons, online <br> collaboration systems <br> Steps: convene a steering committee, engage the public, <br> receive and judge entries, recognise finalise and the <br> share/implement solutions |
| Writing a proposal | Illustrating the contribution to impact <br> Measurable success <br> Result-based budgeting <br> Value for money <br> Risk management |


|  | Author name Focus ngs/conclusions | Year Key | Setting |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: |
| 1 | Sharma et.al., | 2015 | English crowdfunding websites | Simplified content analysis of online crowdfunding campaigns for randomised controlled trial funding | 1. Most crowdfunding campaign funding targets are achieved <br> 2. Crowdfunding is effective to rapidly raise funds for RCTs <br> 3. $95 \%$ of campaigns use a flexible model where campaign creators keep all the funds raised <br> 4. Crowdfunding may be useful for pilot or phase 1 studies when funding from government agencies is insufficient. |
| 2 | Aleksina | 2019 | North America only | Mixed methods analysis of correlates of crowdfunding success in crowdfunding campaigns hosted by <br>  and Cohsentho (morrigaofit) only | 1. Communication, social networks, and the engagement of a large audience via social media are essential tools for successful crowdfunding <br> 2. Campaigns hosted on Experiment.com were more successful than those on Consano, possibly because Experiment is a larger platform, with a higher number of potential <br> Amplidmu <br>  preferred, even if they are profit-orientated and charge a fee (Experiment.com) <br> 3. Projects with higher funding targets and those using an innovative approach are less likely to reach their target as donors remain risk averse. <br> 4. Crowdfunding in medical research disregards the disease characteristics and the total value delivered to phe society. Researchers anan therefore be successfult in crowdfunding a wide range of projects. <br> 5. Stated charitable attitudes and behavior cannot be used to forecast actual donation behavior in crowdfunding medical research. |
| 3 | Krittanawong | 2018 | Top online crowdfunding websites in English (based on site volume) | Simplified content analysis of online crowdfunding campaigns to assess the \&easibBitynef uxing, 2014 crowdfuedling.fferica cardiovascular research | 1. More than half of crowdfunding campaigns for cardiovascular disease research are unsuccessful. <br> 2. Factors associated with low success included the lack of an easy-to-understand message or campaign video. <br> 3. $\$ 5000$ to $\$ 10000$ is the average amount raised for crowdfunded cardiovascular research. <br> 4. Crowdfunding is most suitable for young investigators looking to conduct pilot studies before applying to larger grants. |
| 4 | Dragojlovic Lynd | 2014 | North America and Europe | Simplified content analysis of ${ }^{1}$ crowdfunding campaigns for y cancer research and rare diseases using mixed methods. | 1. The data suggests that crowdfunding is a viable approach to supporting early-stage proof-of-concept research for both common and rare cancers and for rare inborn genetic diseases. <br> 2. Such an approach could become a valuable additional source of funding for innovators in the drug development arena. Researchers would be well served by splitting their broader |

research program into a series
of smaller discrete projects that could be funded by multiplecrowdfunded grants.
3. By crowdfunding early-stage research, innovators might be able to validate their approach,making their projects more competitive in traditional grant competitions and making potential
therapeutic interventions more attractive investments for pharmaceutical

## ompanies and other

 investors4. Two potential limitations of crowdfunding:

- Rare disease research may be disadvantaged in the crowdfunding arena because donorsmay have a personal stake in the research may be a driver of donor behaviour
Researchers may not perceive crowdfunding
long-
term
attent
on to buildi
ng a
social media profile
ies - (1) Researchers can partner with experienced foundations whospecialise in marketing and fundraising.
(2) University fundraising units are increasingly creating their own crowdfunding portals and will likely be able to provide support and expertise.

1. A strong social media network, an active outreach process to networks, as well as engagement within the study all correlated with a higher success rate.
2. Amplify Hope donors were more likely to support projects that were near their fundraising goals, and they found video far more effective for learning about genomics than any other medium.
3. The study hypothesises that the crowdfunding campaign may have increased the public's knowledge on genetic sequencing and rare diseases.
4. Limitations of crowdfunding included the difficulty of raising funds when the patient population is small, the time and effort dedicated to raising funds, and the need for a strong network and contacts.
5. Public engagement and effort on multiple fronts (e-mail, press contact, social media) to engage a large audience are important for funding success.
6. According to qualitative data, scientists doubted that their engagement efforts were successful.
7. Projects usually raise small grants, but there is potential to increase funding amounts. Crowdfunding opens up a new pool of funds for pilot or high-risk projects, allowing a scientist to later leverage their engaged audience alongside preliminary data for larger pools of funds.
8. Many \#SciFund projects were on topics that are not normally considered popular with the public - therefore persistent engagement may build an audience for many kinds of projects.
9. \#SciFund illustrates that fostering a strong connection between science and society within the culture of academia can benefit both universities and scientists financially and increase public science literacy.
10. To be competitive in the new and dynamic crowdfunding environment, universities must find ways to develop and enrich policies and practices that foster active outreach and engagement by their faculty.
$7 \begin{array}{lll}\text { Sauermann } \\ \text { et.al., }\end{array} \quad 2019 \begin{aligned} & \text { Global (89\% of } \\ & \text { Experiment.com }\end{aligned}$ xperiment.com campaigns are US-based)

Standardised content analysis of a sample of
Experiment.com projects, with a qualitative analysis of the correlates of funding success

1. Crowdfunding is used primarily by students and junior investigators, for smaller projects
2. The success rate of the campaigns in the sample is $48 \%$ (higher than NIH grant applications and Kickstarter)
3. Students, junior investigators and women have higher odds of reaching their crowdfunding goals. Results support the view that crowdfunding of scientific research broadens access to resources for groups that have been excluded or disadvantaged in traditional funding systems
4. Projects with higher funding targets have lower odds of success.
5. Projects featuring a video presentation, offering rewards, and those with published lab notes and researcher endorsements have higher odds of success.
6. Conventional signals of quality-including scientists' prior publications and project risk have little relationship with funding success, suggesting that the crowd may apply different decision criteria than traditional funding agencies
7. Limitations - the crowd may fund projects that are in legal/political grey zones; crowdfunding side steps traditional peer review; creators may not understand or follow guidelines for ethical research.

Qualitative survey and analysis of the stated preferences of crowdfunding donors in North America

1. Respondents indicated a preference for donating to projects conducted by nonprofit research organizations, and an openness to donating to companies that have a 'for-benefit' corporate structure
2. Potential donors were more likely to support non-profit organizations, projects where the university of the lead researcher had an excellent reputation and where other funding was available. Donors also showed a strong preference for projects that have the potential to yield a curative therapy, and that focus on common and paediatric diseases.
3. Donors prioritise treating disease that are deadlier, have more impact on patients' quality of life, and for which there is a greater unmet need (remember these are stated preferences)
4. Donors prefer donating to friends/family, or with individuals/organisations with whom they already have a relationship.
5. Whilst this study is useful to identify donors' stated preferences, this may not reflect donors' actual behavior (see Aleksina et.al.,).
6. Presenting strong relevant news factors in project proposals, such as the use of graphical materials (pictures, videos) and humour, is correlated with crowdfunding success
7. One way and especially two-way feedback mechanisms between researchers and backers increase project funding
8. Positive endorsements of the researcher or project and quality signals (academic titles and length of the project description) do not increase funding success.
9. Researcher honors or awards, the promise of rewards and the existence of testimonials are not significant drivers of crowdfunding success.
10. The more information a backer has to relinquish to make a donation, the less successful the project will be.
11. Projects with lower crowdfunding goal are more likely to be successful.
12. Campaigns are more successful on crowdfunding platforms that are focused on scientific projects. No disciplinary field receives less or more in terms of crowdfunding for research. In addition, the amount of views the project gets is not correlated with project success.
13. Sharma et al 2015

| A. Validity | 1. Research aim statement | To explore the success of research crowdfunding campaigns by assessing top online (based on site volume) English crowdfunding websites | Y |
| :---: | :---: | :---: | :---: |
|  | 2. Qualitative methodology relevant | Yes- Qualitative/descriptive analysis employed with narrative analysis and presentation of finding given here. Descriptive frequencies provided as relevant. | Y |
|  | 3. Appropriate research design | Qual observational article with some basic descriptive frequencies included. Researchers provide a narrative presentation of findings. | Y |
|  | 4. Recruitment strategy appropriate | Data obtained from medical research crowdfunding websites: Experiment, Consano, Petridish, and Cancer Research UK. They searched these crowdfunding websites using the following search terms:" clinical study"," randomized clinical trial", and" research". | Y |
|  | 5. Data collection appropriate | They also independently established whether a campaign met the eligibility criteria of funding for a clinical RCT that was led by an academic or research institution. A consensus process to resolve disagreements was established. | Y |
|  | 6. Relationship between researchers/ participants | One of the researchers had employed crowdfunding methods which could potentially impact on researcher on bias and the influence that researchers could have had on the research. No statement on how bias was addressed in their reporting. | N |
| B. Results | 7. Ethical issues taken into consideration | Ethics not formally applied for or stated in report. Supporting documents showing further data analysis were made available as online appendixes | N |
|  | 8. Data analysis rigorous | Relevant to study topic however evidence is not from primary studies, taking on limitations from original studies | Y/N |
|  | 9. Clear statement of findings | Provides a convincing conclusion, inclusion criteria not clearly stated Retrieved campaigns from only the top online platforms and limited to English language, rather small number of campaigns selected $\mathrm{n}=20$ | Y |
| C. Usability/ relevance | 10. Value of the research | Correspondence paper, not original research, but valid review results are presented here rather small number of campaigns selected $\mathrm{n}=20$ | Y |

2. Aleksina et al, 2019 (CASP checklist for qualitative research)

| A. Validity | 1. Research aim statement | Abstract: 'To inform researchers applying for this complementary source of research funding, we investigate the determinants of successful crowdfunding campaigns in medical research.' | Y |
| :---: | :---: | :---: | :---: |
|  | 2. Qualitative methodology relevant | Yes - Qualitative methodology is appropriate for this study as the determinants of success are qualitative variables and the data will benefit from qualitative analysis. The research is based on the stated preferences of donors from the Dragojlovic et al study (2016). It shows that none of the attributes found in that 2016 study were in fact useful in predicting the success rate of crowdfunding campaigns. | Y |
|  | 3. Appropriate research design | The decision to use qualitative analysis was not explained. The researcher did however explain why they used ordinary least squares regression to identify success factors. <br> All the qualitative variables were justified/backed by relevant citations, and a detailed explanation was provided for each one. | Y/N |
|  | 4. Recruitment strategy appropriate | Data comes from the Consano and Experiment.com platforms, which authors explain were chosen after an assessment of the content and suitability of these platforms. The four criteria for inclusion were also clearly provided in the Methods. | Y |
|  | 5. Data collection appropriate | Authors state that 'data were collected manually'. The methodology of data collection and full data set is made available online. | Y |
|  | 6. Relationship between researchers/ participants | The paper states in the limitations that 'researchers independently determined the value of the variables in the data set, but that the estimates may be biased. Data was obtained from online sources that were publicly available. Apart from this, there is no reflexion on bias and the influence that researchers could have had on the research. | N |
| B. Results | 7. Ethical issues taken into consideration | No ethics statement is made and there is no attempt to raise issues surrounding consent or confidentiality (however all data was available publicly online) | N |
|  | 8. Data analysis rigorous | The data analysis process is described briefly (OLS regression). There is no theoretical framework but findings are compared to existing evidence. The final sample includes 109 projects from Experiment.com and Consano. Each of the variables included in the data pool are justified and backed up by existing literature or by the Dragojlovic and Lynd et al paper. | Y/N |
|  | 9. Clear statement of findings | The 'concluding remarks' at the end of the paper clearly state the research findings, namely the determinants of crowdfunding success. Multiple sources of data were used (triangulation). The findings are discussed in relation to the original research question and are compared to existing evidence. <br> 'We showed that crowdfunding in medical research dis- regards the disease characteristics and the total value delivered to the society. In crowdfunding, scientists with large social networks, either personal or professional, are more likely to achieve their fundraising goal. Scientists who managed to develop good net- working skills and/or their research became covered broadly across the media and have greater chances to succeed. ' | Y |
| C. <br> Usability/ relevance | 10. Value of the research | Based in North America only. <br> The authors discuss how crowdfunding can contribute to current practice (government research funding) and make recommendations on how funding agencies can learn from crowdfunding. There is no discussion on areas for further research or how the findings can be transferred to other populations. | Y |

3. Krittanawong et al (CASP checklist for qualitative research) - this was not a pure qualitative research paper, but the same checklist was used for homogeneity purposes

| A. Validity | 1. Research aim statement | 'our goal was to explore the feasibility of crowdfunding for the support of cardiovascular research' | Y |
| :---: | :---: | :---: | :---: |
|  | 2. Qualitative methodology relevant | A very short article - not qualitative methodology, more descriptive analysis and review of cardiovascular crowdfunded research projects, with a short statistical analysis for correlates of funding success. <br> In assessing feasibility, a survey among participants may have been a helpful addition. | Y/N |
|  | 3. Appropriate research design | The research design seems appropriate, but in order to assess feasibility, qualitative methods may have been helpful, to get the lived experiences of the researchers completing these CVD crowdfunding campaigns | Y/N |
|  | 4. Recruitment strategy appropriate | Search strategy detailed in the Methods, including search terms and explanation of exclusions/conflicts | Y |
|  | 5. Data collection appropriate | Data collection methods not discussed here - it just states that 3 researchers reviewed the projects included in the study | N |
|  | 6. Relationship between researchers/ participants | Not discussed here. | N |
| B. Results | 7. Ethical issues taken into consideration | No ethics statement/informed consent/confidentiality issues discussed | N |
|  | 8. Data analysis rigorous | Statistical analysis detailed briefly. Lacks a table detailing finding. | Y/N |
|  | 9. Clear statement of findings | Three main findings: <br> 1. Half of crowdfunding campaigns for CVD research are unsuccessful <br> 2. The average amount raised with crowdfunding for CVD research compared with other platforms is $\$ 5 \mathrm{~K}$ to $\$ 10 \mathrm{~K}$ (Crowdfunding may benefit trainees or young investigators as the average of individuals who are likely to contribute to crowdfunding initiatives is 25 to 34) <br> 3. Crowdfunding may be particularly useful for pilot studies before applying for public research grants, particularly for young investigators | Y |
| C. <br> Usability/ relevance | 10. Value of the research | Findings are compared to available literature and are used to recommend areas for future research. | Y |

4. Dragojlovic and Lynd 2014

| A. Validity | 1. Research aim statement | To review the scope and success of existing efforts to crowdfund drug development in oncology and rare diseases, and evaluate the potential for crowdfunding to become a viable source of support for early-stage drug discovery in the future | Y |
| :---: | :---: | :---: | :---: |
|  | 2. Qualitative methodology relevant | Yes- Descriptive study and employed narrative synthesis and analysis of finding given here. Descriptive frequencies provided as relevant | Y |
|  | 3. Appropriate research design | Presents descriptive data on 125 crowdfunding campaigns aimed at financing research in oncology (including basic research, drug discovery, and clinical trials). Also describe five campaigns that have succeeded in raising substantial funds | Y |
|  | 4. Recruitment strategy appropriate | They searched all publicly accessible crowdfunding websites to identify all active or expired crowdfunding campaigns related to drug development research listed between 25 October 2013 and 8 November 2013. Exclusion criteria stated in their methods | Y |
|  | 5. Data collection appropriate | Data for this work was retrieved from crowdfunding campaign websites which provides relevant data for the study aim | Y |
|  | 6. Relationship between researchers/ participants | This was not clearly stated on their report. No statement on how this was addressed either | N |
|  | 7. Ethical issues taken into consideration | Yes- the review both on going and past campaigns and excluded campaigns that failed to raise at least $1 \%$ of their target from the analysis to avoid ambiguous results | Y |
|  | 8. Data analysis rigorous | Clear presentation of sources of primary data retrieval, high relevance to study topic. Logical data analysis and presentation given. Sufficient amount of campaigns $\mathrm{n}=125$ across different platforms provides and adequate basis to support the findings and conclusion | Y/N |
|  | 9. Clear statement of findings | Yes- results clearly presented with relevant interpretations of the study findings | Y |
|  | 10. Value of the research | The research findings add to the body of knowledge on the value of crowdfunding a valuable additional source of funding for early-stage researchers and innovators | Y |

5. Ortiz et. al., 2018 (CASP checklist for qualitative research)
A. Validity $\quad$ 1. Research aim Objective is presented in the abstract

## statement

2. Qualitative
methodology
relevant
3. Appropriate research design
is presented in the abstract
5 objectives in the Methods section: to (1) provide demographic information on the donor population; (2) identify common factors among successful medical crowdfunding campaigns; (3) identify factors that influenced people to donate, as reported by donors; and (4) describe the impact crowdfunding campaigns had on donors' self-reported knowledge of genomics.
Needs assessment: The purpose of all interviews was to establish crowdfunding best practices, elicit recommendations, and develop materials for the training program phase of the study.
The researchers wanted to get insight from experts and researchers that were successful in conducting their crowdfunding campaign. They used telephone interviews for this which seems relevant. They also used surveys to assess participants/donors' perspective on their crowdfunding efforts. Qualitative methodology seems relevant here.
There is no justification on the choice of study design. However, the needs assessment was justified, and the purpose of the interviews was N explained.
The research design seems adequate:

- a needs assessment was conducted through 25 30-minute phone interviews with experts/founders of crowdfunding platforms
- a survey was conducted among participants to assess baseline vs post-crowdfunding knowledge on genomics (only 11 participants overall)

|  |  | -an anonymous survey was sent to donors after they donated to assess demographics and their knowledge of genomics |  |
| :--- | :--- | :--- | :--- |
|  | 4. Recruitment <br> strategy <br> appropriate | Participant recruitment was detailed. Recruitment documents were made available in supplementary material. <br> Experts/successful participants were contacted specifically because they had founded crowdfunding platforms or had relevant expertise. <br> The participants for the crowdfunding trial were recruited through 13,452 emails to rare disease advocacy groups and genetic counsellors, in order <br> to give undiagnosed patients, the opportunity to participate. |  |
|  | 5. Data <br> collection <br> appropriate | The data collection strategy was detailed for the participant and donor surveys (The donor survey was made available in supplementary data). The <br> telephone interview guides were not provided or justified in the main body of text. <br> Data collection through telephone surveys was appropriate but there seems to have been no standardised method of recording the data. | Y/N |
|  | No discussion on bias. There is mention of the limitations of using a small patient population (rare diseases) for recruitment. Authors admit that <br> statistical power is limited here. | Y |  |
|  | 7. Ethical issues <br> taken into <br> consideration | No ethical approval/confidentiality agreement/informed consent explanation. |  |
|  | The data analysis strategy was not given. No thematic analysis. There is some discussion on potential bias related to the small sample population. <br> They could have formally assessed the qualitative data collected during the 25 30-minute interviews as these would have provided more insight <br> into what makes a successful campaign from the point of view of experts. | N |  |


|  | 9. Clear <br> statement of <br> findings | There is clear statement of the findings, including comparison with existing literature on crowdfunding and in relation to the original research <br> question. There was a very limited assessment of credibility (see above) <br> 'We found that social media played an important role in all campaigns. Specifically, a strong social media network, an active outreach process to <br> networks, as well as engagement within the study all correlated with a higher success rate. Amplify Hope donors were more likely to support <br> projects that were near their fundraising goals, and they found video far more effective for learning about genomics than any other medium. |
| :--- | :--- | :--- | :--- |
| C. <br> Usabilit <br> y/ <br> relevanc <br> e10. Value of the <br> research | Paper makes recommendation on how this study can contribute to the existing literature on crowdfunding and how it can be used. It also <br> recommends areas for future research. |  |

6. Byrnes et. al., 2014 (CASP checklist for qualitative research was used - only the qualitative data was appraised, all quantitative data was excluded if not relevant)Strong quantitative methods, but lack of formal qualitative analysis of survey results -

| A. Validity | 1. Research aimstatement | Based on the \#SciFund challenge <br> 3 objectives outlined in introduction: 'We therefore set out to ask how the amount of money one could raise via crowdfunding is influenced by: <br> 1) building an audience for one's work via science communication <br> 2) the amount of effort put into communicating one's science, and <br> 3) the different avenues one used to communicate their work.' | Y |
| :---: | :---: | :---: | :---: |
|  | 2. <br> Qualitative methodolo gyrelevant | This study was in fact mixed methods, but we focus on the qualitative methodology. The qualitative aspect is justified as the subjective experiences of the SciFund challenge participants is of interest here. The quantitative measures used are also helpful for the study objective. | Y |
|  | 3. Appropriate research design | The authors designed a survey to measure various aspects of crowdfunding from the participants' perspective. There are specific objectives that are outlined for the survey. | Y |
|  | 4. Recruitment strategy appropriate | The process for recruiting scientists to the challenge was described in detail and there is a table detailing project distribution and the various rounds of the SciFund Challenge. The participants in the final challenge then answered survey questions. <br> 'The survey was answered by 47 of the 49 \#SciFund round one participant, 48 of 75 round two participants, and 22 of 35 round three participants.' <br> One outlier project was excluded from the data and this was explained in detail. | Y |


| 5. Data collection appropriate | [QUANTITATIVE: data sources are outlined in detail: 1) web visit and donation logs of each crowdfunding project from RocketHub (platform, with dedicated section just for the SciFund challenge) ; 2) publicly available info from the internet (Twitter, Facebook number of likes/tweets) <br> 3) the number of times project videos were viewed (quantitative measures) ] <br> QUALITATIVE: Survey - the authors provide the full list of questions (based on strategies used to create crowdfunding materials, strategies used to promote campaign, social network size and ongoing online outreach activities) - for all participants of the SciFund challenge. Survey included qualitative questions and quantitative questions. <br> The survey instrument was updated, and this is outlined in the Methods as well: 'The survey instrument for rounds two and three differed in some ways from the instrument we used for round one. [...]' <br> 'We therefore revised several questions in our survey in order to better assess participant effort for rounds two and three. We were thus able to ask, how does effort modify the effect of audience size on the ability of a researcher to bring people to view their project?' | Y |
| :---: | :---: | :---: |
| 6. Relationship between researchers/ participants | There Is no discussion on bias here. <br> Authors declare 'no competing interests' - 'The organizers of \#SciFund were not paid by RocketHub nor did they receive any funds, either directly or indirectly, from \#SciFund participants or donors (other than the donor funds Walker, Byrnes, and Faulkes received from their individual projects (as participants of the challenge)).' <br> Authors did change the survey across rounds to adapt to the survey responses they received | $\mathrm{Y} / \mathrm{N}$ |
| 7. Ethical issues taken into consideration | No discussion on ethics/informed consent/confidentiality here | N |
| 8. Data analysis rigorous | There is extensive description of the data analysis process for the quantitative analysis - including the hypotheses researchers made and a detailed explanation of the quantitative methods used. <br> Four stat models (linear models were used) were used to answer four questions: <br> 1) What effect did the number of donors have on crowdfunding success? <br> 2) Where were donations coming from? <br> 3) Was the attention a project received generated from existing social networks or other forms of 'buzz' generated by the SciFund campaign itself? <br> 4) Did long term scientific outreach via blogging increase scientists' outreach-generated social networks <br> NO METHODOLOGY ON QUALITATIVE DATA ANALYSIS IS AVAILABLE and authors only state that the qualitative data was compared to the stat models in order to determine if participant perceptions about crowdfunding success/failure matched the results of stat models. | N |
| 9. Clear statement of findings | The quantitative results are well displayed <br> The qualitative results are briefly explained in the final paragraph, but there is no methodology/framework for data analysis - two Tables (11 and 12) show factors that helped and hurt project fundraising - | N |

10. Value of the
research

The one positive aspect is that qualitative results were compared to statistical analysis quantitative results

Most projects included in analysis were on Conservation biology and ecology (100) (only $\sim 25$ were related to health
Extensive discussion on study results and comparing quantitative measures to participants' perceptions (especially regarding campaign effort) Some discussion on survey limitations in the Discussion and where the authors fell short Limited comparison to existing literature
Study explains how this SciFund challenge contributes to current practices in research funding + gives recommendations for the future
7. Sauermann et al 2019

| A. Validity | 1. Research <br> aim <br> statement | To provide new evidence on the state of crowdfunding in scientific research and should be of interest to <br> social scientists aswell as to scientists who consider starting their own crowdfunding campaigns. By <br> providing empirical evidence from the specific context of science, this study also contributes to the broader <br> literature on crowdfunding, which tends to focus on general-purpose platforms. |  |
| :---: | :--- | :--- | :--- |
|  | 2. Qualitative <br> methodology <br> relevant | Mixed methods with descriptive analysis. To assess the potential of crowdfunding for scientific research, the <br> authors first <br> reported initial evidence from Experiment.com, They build on this existing work to provide insights into <br> crowdfundingcampaigns in an understudied context-scientific research | Y |
|  | 3. Appropriate <br> researchdesign | Mixed methods with descriptive analysis. An initial research was conducted to identify themes ahead of their <br> data collectionand analysis | Y |
|  | 4. Recruitment <br> strategyappropriate | They searched all publicly accessible crowdfunding websites to identify all active or expired crowdfunding <br> campaigns relatedto drug development research listed between 25 October 2013 and 8 November 2013. <br> Exclusion criteria stated in their methods | Y |
|  | 5. Data <br> collection <br> appropriate | Data for this work was retrieved from crowdfunding campaign websites which provides relevant data for the <br> study aim. Theyprovide descriptive information on the creators seeking funding, the projects they are seeking <br> funding for, and features of the crowdfunding campaigns. Then they investigated how these various <br> characteristics are related to campaign success. <br> They compared the results to prior research on the predictors of fundraising success in crowdfunding but also to <br> research ontraditional scientific funding mechanisms such as government grants. And finally examined whether <br> and how predictors of crowdfunding success differ from those that predict attention from a more professional <br> audience-journalists covering scientific research |  |


| B. Results | 7. Ethical issues <br> takeninto <br> consideration | Yes- permission obtained to share data publicly. IRB application for the work was not reported anywhere in <br> the report. Creator characteristics and project characteristics reported separately. They also provide empirical <br> evidence from the specificcontext of science, |  |
| :--- | :--- | :--- | :--- |
|  | 8. Data analysis <br> rigorous | Rigorous data analysis, additional variables were coded based on project description high relevance to study <br> topic.Incomplete data sets were removed, and final campaign data included in analysis was 725 campaigns | Y |
|  | 9. Clear <br> statement of <br> findings | Yes- results were interpreted and a clear statement of their finding presented "Our results highlight significant <br> opportunities for crowdfunding in the context of science while also pointing towards unique challenges. We <br> relate our findings to research | Y |
|  | on the economics of science and on crowdfunding, and we discuss connections with other emerging <br> mechanisms to involve the public in scientific research" |  |  |
|  | 10. Value of the <br> research | The findings highlight important differences between crowdfunding and traditional funding mechanisms for <br> research, including high use by students and other junior investigators but also relatively small project size. <br> This validates some earlier findings published in other crowdfunding studies. this study also contributes to <br> the broader literature on crowdfunding, which tends to focus on general-purpose platforms |  |

8. Dragojlovic and Lynd, 2016 (CASP checklist for qualitative research)
alidity esearch aim : to help inform the fundraising strategies adopted by biomedical research organizations that are considering the use statemen of crowdfunding, we conducted an online survey of potential North American donors to identify the types of drug development research projects that prospective donors might find most appealing.' Gap in the literature identified and attempt by the authors to fill it.

| ualitative 1odology relevant | litative methodology was appropriate here as the research aimed to collect preferences from individual donors. |
| :---: | :---: |
| ppropriate research design | 1ors did not justify the study design. Presents a very biased picture of donor preferences as they are explicitly asked for these. Stated preferences may deviate from revealed preferences. |
| ecruitment strategy appropriate | s USA was in charge of recruitment (a leading survey research firm). A screening questionnaire was used to oversample respondents who had previously donated money to support medical research. Samples included an approximately equal number of male and female respondents. -e is limited discussion around recruitment however: we are told that 168 respondents were excluded (with explanation), yielding a usable sample of 814 respondents. |


|  | ta collection appropriate | $e$ is a very detailed explanation of the data collection tool (online survey) and how scoring was done for the responses. There is no justification of the methods used or a discussion on saturation of the data. |
| :---: | :---: | :---: |
|  | lationship between researchers/ participants | authors explain an external company 'Ipsos' completed the recruitment of the study. There is limited discussion on potential biases with a reflection on the composition of the Ipsos panel, non-response bias and the exclusion of francophone residents in Canada. |
| esults | hical issues taken into consideration | thical statement or discussion on informed consent/confidentiality |
|  | ata analysis rigorous | data collection strategy and how scores were used was explained in detail in the main body of the research. The data analysis strategy itself is not that detailed. A sample of $\mathbf{8 1 4}$ surveys were used. There is a discussion on bias. |
|  | ear statement of findings | findings are explained in detail and are compared to existing literature. |


| 9. M. Schafer et al, $\mathbf{2 0 1 6}$ (CASP checklist for qualitative research) |  |  |  |
| :--- | :--- | :--- | :--- |
| A. Validity | 1. Research aim <br> statement | Abstract 'The study at hand identifies and tests explanatory factors influencing the success of scientific crowdfunding projects by <br> drawing onnews value theory, the "reputation signalling" approach, and economic theories of online payment." |  |
| 2. Qualitative <br> methodology <br> relevant | Standardised content analysis, which is a qualitative methodology, was used for this research. The paper uses four theoretical <br> frameworks to organise and analyse the findings (as a conceptual framework to explain crowdfunding success of scientific projects did <br> not exist): 'news valuetheory, reputation signalling, theories of online payment and social factors' |  |  |
|  | 3. Appropriate <br> research design | The authors do not discuss the rationale behind the use of standardised content analysis for this research. <br> However, the research design does seem appropriate - the researchers used specific theoretical frameworks to guide their qualitative <br> analysis.They explain that the codebook they used was organised according to these frameworks. |  |
|  | 4. Recruitment <br> strategy <br> appropriate | There is a detailed description of the study search, inclusion and exclusion criteria (done by 4 researchers using key terms). There is a <br> tabledetailing all the crowdfunding platforms included in the analysis and the number of scientific projects per platform. |  |
|  | 5. Data <br> collection <br> appropriate | There is limited detail on how the data was collected. 371 projects were analysed across 11 crowdfunding platforms.6. Relationship <br> between <br> researchers/ <br> participants | No discussion on bias - the authors state that 4 coders participated in coding the projects using specific variables and that intercoder <br> reliabilitywas calculated. |
| B. Results | 7. Ethical issuestaken <br> into consideration | No ethical statement/confidentiality or informed consent discussion (however all data was available publicly online) |  |

Appendix V: Risks in crowdfunding and our mitigation strategies from the TDR pilot

## Risks identified Risk mitigation strategies from our TDR pilot

|  | 1) Researchers obtained support from local experts |
| :---: | :---: |
| Fraud and deception | 2) Researchers secured IRB approval prior to crowdfunding launch <br> 3) TDR Global and the researcher's platform worked in partnership with a crowdfunding platform to facilitate LMIC fundraising |
| Spreading misinformation | 1) Researchers employed open access tools to disseminate findings <br> 2) Communicated process and results clearly |
| Fair allocation of funds | 1) Researchers included result-based budgeting in the proposal and on the launch page <br> 2) Transparent engagement with backers and the public during the campaign and afterward <br> 3) Illustrating the contribution to impact and measurable success <br> 4) Partnerships with experts |
| Lack of interest in project | 1) Researchers created video pitches with storytelling for public engagement which included personal stories |
|  | 2) Researchers expanded the network of people engaged with their research, built collaborations and mentorship |
|  | 3) Communicated the process and results to a broader and new audience. |

