

Utilization of the Crowd for Medical Research

The internet and social media have transformed life, as we know it.

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Facebook, twitter, blogs, online videos, podcasts, tagging, wikis, search engines – all of these digital age tools have made people more interconnected and information more accessible than ever before. As a result, the concept of using the crowd as a resource for funds and ideas has made major inroads into modern society, being utilized in such diverse fields as journalism, law enforcement, product design, graphic design, architecture, and much more. Recently, some have begun to explore the utilization of the crowd for various purposes in medical research, including fundraising as well as crowdsourcing for intellectual analyses and insights.

Due to strict regulations and the rigorous nature of research, utilization of the crowd in medical research has not been as prevalent as in other fields. Nonetheless, there are a number of innovative ways that the crowd is being used to advance medical research, serving to reduce costs, improve quality and fund promising projects. So, how is the crowd being utilized? What are some of the trends we are seeing? What are the unique challenges in research that inhibit organizations and individual researchers from turning to the crowd? And given some highly publicized successes to date, what is the future likely to hold?

A Need for Speed

While the drug discovery process is experiencing substantial rising costs, government funding for medical research has declined significantly in recent years due to federal budget cuts. According to a report from the Congressional Research Service, only 19 percent of projects submitted to the NIH were funded as of 2011, for example. This is down from 33 percent in 1997. The American Association for the Advancement of Science has reported that federal support for all research and development fell 16 percent in inflation-adjusted dollars over the past five years. There is currently a crisis of funding in medical research – labs are downsizing, research projects being shut down, researchers are retiring early, and young scientists are being discouraged from pursuing research careers.

All of these trends have created significant roadblocks to funding for many medical researchers. One possible solution which holds promise is crowdfunding.

Crowdfunding and Medical Research

Crowdfunding platforms like Kickstarter have been used to fund business startups for artists and others who have created products that are marketed to the public. Those who donate to the project typically receive a nominal gift in exchange for the donation, which may even be the product in question for a large enough donation. Although Kickstarter has been used to fund scientific research projects with limited success, other platforms appear more suited to funding science.

The nonprofit crowdfunding platform known as Consano uses a scientific advisory board to vet research projects. Once approved, projects are loaded up on the Consano website where they are available for donations. Consano funds its overhead from corporate partnerships, foundation grants, and private donations. FutSci, is a platform created and run by scientists who want to support innovative research in the Life Sciences. To fund overhead, FutSci takes a 7 percent fee should a project meet its funding goals. The Amplify Hope platform was created by the Rare Genomics Institute in an effort to help families fund genomics research into rare diseases. Selected families have been trained, supported and coached on crowdfunding strategies. The Amplify Hope program is funded by various Foundations. Another platform, Experiment.com, offers a promising science funding platform where multidisciplinary researchers can solicit the public for funding. Researchers can register for free to present their own projects that need funding. Backers fund directly to the scientists, so there is no middleman or overhead involved.

However, the platform is an all-or-nothing funding mechanism, meaning that the project must reach the funding target or no one's pledges are charged. Bill Gates, a long-time philanthropist and medical research advocate, commented that, "This solution helps close the gap for potential and promising, but unfunded projects."

Indeed, there are a wide variety of platforms out there that are available to raise funds for scientific research. But there are challenges. Crowdfunding for medical research typically does not have the glamour or wide-spread appeal of creative artistic projects with unique products that have been used to raise vast sums of money through platforms like Kickstarter. Typically, crowdfunding for research projects brings in only modest amounts of funds. A recent review reported that on average, only about \$6,000 per campaign was raised for scientific research. Another review found that 97 crowdfunding campaigns focused on cancer research raised around \$45,500 on average. The larger amounts raised in this case are due to alliances between researchers and existing medical research foundations, who are typically much better positioned to raise necessary funds.

The amount that can realistically be raised for medical research will depend on how appealing the project is to potential donors, and on how big an audience is connected with the project, but will most likely be \$10,000 or less. As a result, crowdfunding for medical research could be a useful model for funding small, catalytic experiments that garner funds and media attention for early stage ideas and high-risk proposals that the current grant systems are hesitant to invest in. Researchers can use crowdfunding as a way to fund the generation of preliminary data and thus best thought of as an adjunct, and not a replacement for traditional funding.

Turning to the Crowd for Research

There are other ways the scientific community is turning to the crowd. Crowdsourcing, an area with many potential applications, is growing in interest in the scientific community. It is based on the idea of collective intelligence, the utilization of the crowds' diverse experiences, knowledge and intellect towards the solution of a problem. One of the benefits of crowdsourcing in the digital age is that it allows investigators to easily engage thousands, or potentially millions, of people to provide either data or data analysis.

Like crowdfunding, utilization of crowdsourcing in medical research has not been as prevalent as in other fields. Nonetheless, there are a number of innovative ways crowdsourcing is being used to further medical research, serving to both reduce costs and improve quality.

Crowdsourced health research studies can be **researcher-organized or participant-organized**. Researcher-organized studies are organized by credentialed researchers using cohorts gathered from health social networks for traditional studies. A powerful example of a researcher-organized study that involved epileptic seizure prediction was recently reported in Discover Magazine. After 15 years of unsuccessful work by the National Institutes of Health to devise a computer algorithm that predicted epileptic seizures, a frustrated group of epilepsy physicians took matters into their own hands and provided datasets from the brains of human epileptic patients and dogs to computer geeks from around the world with an invitation to develop a seizure prediction algorithm. Three months later, prize money was distributed to the winners who had produced an algorithm that predicted seizures with better than 84% accuracy.

Participant-organized studies are also making an impact in the health care industry, with the rise of what has been termed "citizen science." That is, individuals with no formal training in the field specific to the topic of investigation have begun organize their own research studies through social networks and health collaboration communities in order to expand knowledge about particular health-related concerns.

One online community, DIYgenomics, is attempting to advance knowledge in the field of preventative medicine by facilitating member-organized studies based on the hypothesis that genetic polymorphisms produce out-of-bounds phenotypic biomarker levels that can be corrected through various dietary, lifestyle or supplement interventions. DIYgenomics currently has 13 such studies in open enrollment, covering a range of conditions including vitamin deficiency, aging, mental performance, longevity, empathy and epistemology.

In addition to internet-based platforms like the one used by DIYgenomics, which allow the automated operation of crowdsourced health research studies, study participant self-tracking tools and their validation and calibration are essential for accurate data collection in crowdsourced clinical research. The online participant-organized research community known as Quantified Self lists over 500 such tools on its website. As access to low-cost data collection tools continues to grow, the number people available for participation in crowdsourced medical research requiring self-tracking could increase significantly.

Crowdsourcing challenges

There are a number of limitations with methods currently in use by researchers in crowdsourced medical research studies. One of the drawbacks is the difficulty in assessing the quality of the data. Much or all of the data used in crowdsourced research is self-reported by study participants. As such, it is often difficult to verify whether the study participant actually has the condition in question, properly followed the intervention protocol, or accurately reported outcome. Clearly, there needs to be clear procedures in place to assure participant-reported data accuracy before evidence from crowdsourced studies can be used for pharmaceutical testing.

Other challenges for crowdsourced health research studies are in the related areas of study protocol and bias. Crowdsourced health research studies frequently do not follow the rigorous protocols of randomized double-blind controlled studies. Many crowdsourced studies do not use blinding or have a placebo component, and some have expressed concern that bias may enter into the data when disease patients collect and report their own data. Such biases may be especially pronounced in participant-organized studies. In addition, crowdsourced study members are often like-minded participants and may thus not be representative of the general population, leading to misleading study conclusions.

Expansion is on the horizon

The impact of crowdfunding and crowdsourcing on the health care industry seems destined to grow over time. Self-experimentation, participant-organized crowdsourced studies, and researcher-organized crowdsourced studies are emerging as complements to traditional approaches – that should be welcomed as a valuable component of a multi-tiered public health ecosystem. From the funding side, as the availability of research funding continues to decline, crowdsourcing may be perfectly positioned to fill an important niche in the medical research community. Though neither crowdfunding nor crowdsourcing is likely to replace the status quo, they are important alternatives with the potential to fund or source innovative approaches, which ultimately drives down cost and improves quality for all of us. That said, the idea of crowdsourced medical research in the digital age is a new concept, and given the challenges, standardized guidelines for health care crowdsourcing ventures are needed so that data can be collected, reported, and replicated most efficiently.



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