Healthcare: Pouring a little cold water on crowdfunding

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Who would have thought that the Ice Bucket Challenge would be credited for bankrolling healthcare breakthroughs? The online campaign, which encouraged participants to be filmed while pouring a bucket of ice water on their heads and then inviting friends to do the same, was started in 2014 by ordinary people as a fun way to raise money for a relative with motor neuron disease, a normally fatal neurodegenerative condition that is also known as Lou Gehrig's Disease, or Amyotrophic Lateral Sclerosis (ALS). The idea went viral, with millions of people, as well as famous presidents and rock stars, joining in. The challenge became the fifth most popular Google search in 2014 and raised more than US\$220 million worldwide. Little wonder the ALS Association credits its recent discovery of a new gene, giving hope for "real, meaningful therapies" for ALS, to the Ice Bucket Challenge.

The success of this campaign is hard to ignore, and while no crowdfunding campaign has come close to matching it, this does not mean the method is without value or impact. The Movember charity is another example. This began in 2003 when two young men in Australia persuaded 30 friends to grow a moustache in November for charity, and is now an annual event. It operates in 21 countries,



and has generated some \$500 million for research into prostate and testicular cancer, while also encouraging men to talk more openly about their health in general.

A key question is whether crowdfunding for medical research is a sustainable solution, or merely the zeitgeist of a generation who live vicariously through social media platforms where "sharing", "liking" and "donating" are a simple click. Are successes like ALS simply arbitrary? After all, the internet is already saturated with Just Giving sites, and littered with causes in dire need of funds. The donating public cannot always be sure about project design, authenticity, standards for data collection, or safety protocols. Nor can they know which cause is more worthy or likely to succeed.

In the US, barely 5,600 people are diagnosed with ALS every year, compared with over 300 000 new cases of breast cancer. Both ALS and prostate cancer have traditionally suffered from low profiles and have had a hard time seeking funding, and the combination of moustaches and ice buckets with social media evidently helped change that.

These movements cannot replace long-term funding for medical research or strategic health programmes such as cancer screening, but crowdfunding can work well if managed by the researchers themselves. As scientists have faced growing competition for a shrinking pot of government research funds, an emerging generation of scientists are leveraging the world of crowdfunding, social media and motivational talks to promote and raise money for research. Moreover, official funding processes can be notoriously slow, so when emergencies ignite, scientists want to work quickly. This was the case for the Zika Virus Challenge, which went live on Experiment, a crowdfunding platform for scientists, in March 2016; all modest targets of \$2,000-\$6,000 were reached.

Larger gains are rare, and quirky campaigns that do not report breakthroughs can lose their appeal, even if worthy. This problem applies less to regular funding, since even if survival rates are low for certain cancers, for instance, there is a public sense that a breakthrough can and must be found. While crowdfunding might not always lead to ice-bucket style successes, by raising awareness and making policymakers realise that basic research funding pays off, then its place in today's fundraising market should be secure.

Visit www.alsa.org, http://experiment.com/grants/zika-virus and http://uk.movember.com/programs/prostate-cancer

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