

Crowdpower in the era of 'health 2.0'

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Abstract

Members of the social web are increasingly banding together and using web 2.0 technologies to actively participate in their own healthcare ('health 2.0'). This article gives an overview of how 'crowdpower' is impacting the field of healthcare, above and beyond merely offering emotional or informational support. It describes how the face of healthcare research is changing due to the technology-mediated collaboration between companies and ordinary patients, and how disease may be prevented with the help of the social web. Issues of health literacy and the role computer gamers are playing in the quest for new therapies are also discussed.

Keywords: Crowdsourcing, Healthcare, Health 2.0, Social health networks, Medical communications, Medical writing

The social web has led to a democratization and acceleration of communication, since information can be exchanged globally and in real time between people from all walks of life. Increasing numbers of people are now using web 2.0 technologies to actively participate in their own healthcare ('health 2.0') in ways that would have been unheard of a few years ago. Members of the social web are harnessing their creativity and launching collective endeavours that will permanently change the face of healthcare. This power of the crowd extends beyond offering emotional support or exchanging information, for example between patients suffering from the same condition. It is equally involved in addressing health literacy issues, promoting research activities, preventing diseases, and even in the quest for new therapies.

Offering emotional and informational support

For patients suffering from rare or chronic conditions, connecting with one another via disease-specific networks can be an invaluable source of

emotional and informational support. A study has shown that almost one in four (23%) Internet users living with high blood pressure, diabetes, heart or lung conditions, cancer or other chronic illnesses go online to find other patients with similar health concerns.¹ There are numerous high-quality blogs by patient experts and/or advocates that all offer a wealth of information: DiabetesMine is a site set up by a woman suffering from type-1 diabetes who shares medical information and practical advice on dealing with the disease.² Crohnology is a social health network for people with Crohn's disease and colitis to learn what treatments work, to meet other patients near them, and to track and share their health.³ The site 'stupidcancer.com' was launched by a young man struck with a rare form of paediatric brain cancer who found himself isolated between the worlds of adult and paediatric oncology. A recent mother with a rare heart condition called spontaneous coronary artery dissection proactively started her own online community, which eventually led the Mayo Clinic to initiate research into the disease.⁴

Addressing issues of health literacy

Crowdpower is also addressing issues of health literacy, or the ability to understand medical or health-related information, in new ways: a German website called 'What'sWrongWithMe', staffed entirely with a group of volunteer medical doctors, translates medical jargon into terms that laypeople can understand.⁵ Although almost 600 specialists are helping to support the site, the demand for this service far outstrips its capacity, highlighting the unbroken need for clear communication to help patients understand their illnesses and make informed decisions about their health. A study from the United States has shown that one in two people only have intermediate skills when it comes to health literacy.⁶ Barriers to understanding include not just difficulties in comprehending specialized medical terminology, but a

limited understanding of math, difficulty in taking in large amounts of information at once, and high levels of emotion and apprehension when dealing with illness in oneself or in a loved one.⁷ This continues to be an area in which professional medical writers and/or communicators can make a valuable contribution by processing and presenting medical information in a manner that not just experts, but laypeople can easily understand.

Crowdsourcing healthcare research

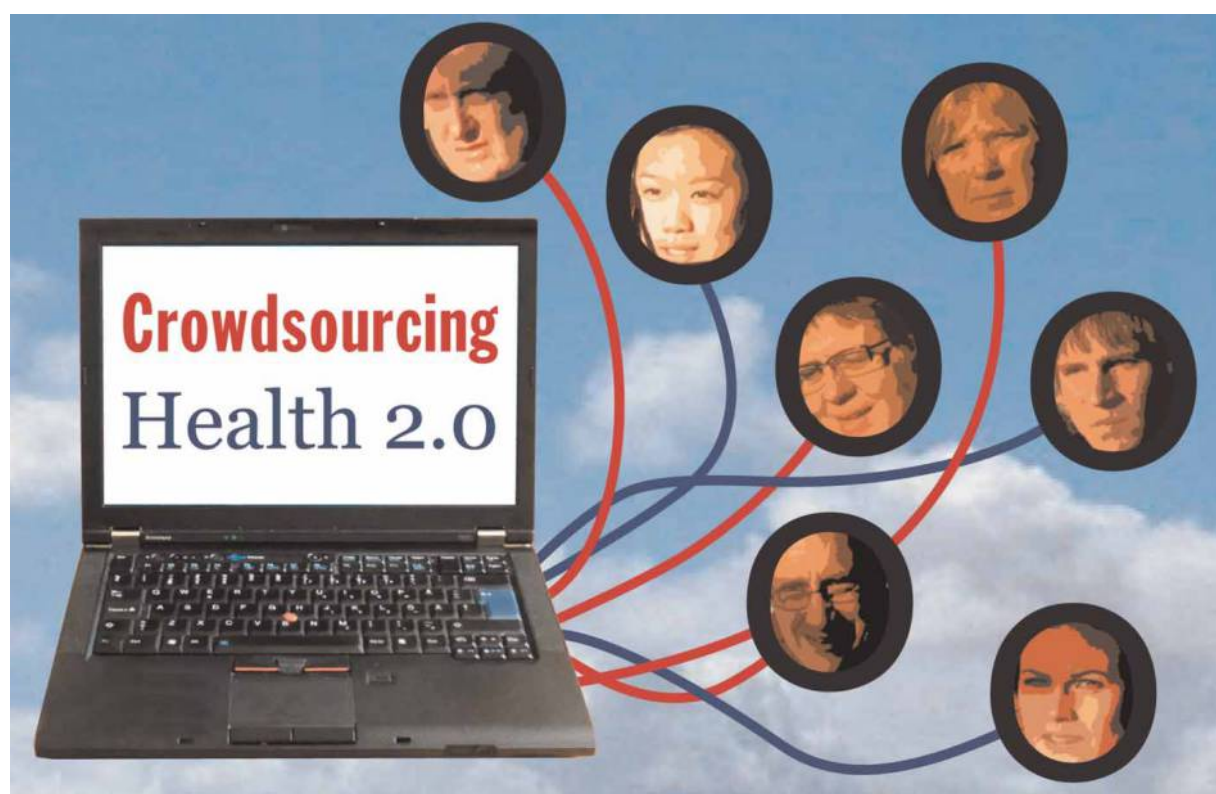
The advent of the social web has led to so-called crowdsourcing, i.e. using web-based technology to recruit large numbers of project participants. In the context of healthcare, crowdsourcing opens up new avenues of patient recruitment for clinical research trials and is a welcome development in the face of notorious difficulties many fields of medical research encounter.⁸ Cancer is one area where finding patients can be especially challenging,⁹ so the 'army of women[®]' is using the Internet to look for women from all around the world interested in taking part in studies on the cause and prevention of breast cancer.¹⁰ What is new is that recruiting is no longer limited to researchers or institutions. In the spirit of 'citizen science', patients motivated by their own health issues are now able to bring their own ideas

into play and initiate trials with the help of web-based platforms.

Organizing research into rare diseases

Two leading players in researcher-organized, crowd-sourced health research studies are PatientsLikeMe¹¹ and 23andMe.¹² PatientsLikeMe offers patients an online platform where they can share their health data and participate in clinical trials. The company generates revenue by anonymizing the data collected and selling it to relevant life science and health management companies. In one widely published example, data collected from a cohort of 150 amyotrophic lateral sclerosis (ALS) patients recruited through PatientsLikeMe succeeded in refuting the results of a previous study with a significantly smaller patient cohort on the effects of lithium carbonate on ALS progression.^{13,14}

23andMe is a for-profit company whose business model is based on genome testing for private customers, combined with a web-based social network that allows people to 'participate in research while exploring your own genetics'. Among others, they have research communities on Parkinson's disease, sarcomas, and myeloproliferative neoplasms that people are free to join, and have published data on the correlation of self-reported medical data with known genetic associations.¹⁵



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Empowering patients to initiate their own studies

In contrast to purely researcher-organized studies, the web now also has platforms for crowdsourcing health research studies where any member (professional or layperson) can initiate a study. One example is DIYgenomics, a non-profit research organization that capitalizes on the fact that sinking costs in genomic sequencing are allowing people to obtain their own genomic data.¹⁶ DIYgenomics is partnering with the start-up Genomera¹⁷ to crowdsource genomic research into topics like vitamin deficiency, ageing, and mental performance. Participants share their genomic and phenotypic information via the website which then collects, analyses, and visualises the study data. The service is free of charge, but the company hopes to generate revenue through referrals, sponsors, and analytic services.

Althea Health¹⁸ is a start-up that provides the infrastructure for people to plan studies via its website and then deploy them on smart-phones. As an initiator, you define the aim of the study and its key parameters (symptoms, observations, treatments etc.), post an enrolment form on the website and are subsequently responsible for recruiting participants. Collected data are aggregated and reported back by the company. Patient-oriented sites like CureTogether¹⁹ and QuantifiedSelf²⁰ focus mainly on bringing together like-minded people interested in learning more about their health or certain conditions, other people’s experiences and better treatment options. Although experts agree that crowdsourced healthcare research can be a useful extension of traditional clinical trials,²¹ the scientific rigor of these kinds of studies must be subjected to careful scrutiny before results are extrapolated to broader populations. The problem of self-report bias and sample sizes in particular are apt to be more relevant in crowdsourced contexts.

Preventing diseases before they spread

People who are knowledgeable about their risk factors and predispositions for certain diseases can be motivated to improve their own outlook. The health 2.0 environment is facilitating access to tailored programs for specific diseases, as in the case of Omada Health, an online start-up focusing on disease prevention.²² Their first web-based program is concentrating on people with prediabetes, i.e. those with blood glucose levels sufficiently high to indicate that they may develop type-2 diabetes. People are divided into small groups and matched with an Omada coach

who guides patients through a 16-week lifestyle course. The aim is to combine the advantages of technology with social support to enhance adherence and thus improve participants’ long-term health outlook.

In the field of pandemic tracking and prevention, search engines can be used to monitor global disease activity,²³ as with Google’s Flu Trends,²⁴ a development which has even caught the interest of international regulatory and control authorities. In a study done during the 2007 H1N1 pandemic in Europe, it was shown that there was a good correlation between the numeric estimates of sentinel physicians and Google’s Flu Trends reports.²⁵ The European Centre for Disease Prevention and Control (ECDC) thereupon ranked Google’s Flu Trends as a useful supplementary tool to monitor pandemics.²⁶

Finding new therapies with gamers’ help

The power of the crowd also comes into play in a field more commonly associated with frivolous nerds than with healthcare – computer games. The online science game FoldIt capitalizes on humans’ superiority over computers in solving three-dimensional problems by asking participants to help fold proteins.²⁷ Gamers have successfully improved enzymes and discovered new strategies and algorithms at their computers which may potentially help scientists find new treatment options for certain diseases.^{28,29}

Conclusion

The social web has spawned a myriad of healthcare-related communities that are exchanging information and getting actively involved in their own health issues. A characteristic of this trend is the blurring of the boundaries between ‘experts’ and ‘laypeople’. Thanks to internet technology, not just medical professionals, but engaged ‘citizen scientists’ can also play a key role in moving science forward. In the world of health 2.0, the power of the crowd is subtly changing many areas of healthcare – from clinical research to disease prevention to the search for effective treatments.

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