

Evaluation of Crowdsourcing in the Field of Medical Research

Vignesh. P

Student

*Department of Computer Science and Engineering
S. A. Engineering College, Chennai*

Mrs. Renuka Devi. M

Assistant Professor

*Department of Computer Science and Engineering
S. A. Engineering College, Chennai*

Nerisai. M. V

Student

*Department of Computer Science and Engineering
S. A. Engineering College, Chennai*

Abstract

Crowdsourcing is a good and efficient source model to obtain goods and services for individuals or organisation. This is very much advantageous over other methods as it helps to learn beyond the base of minds of the people. This model is widely used in various research fields like astronomy, ornithology, seismology, medicine etc., in the present medical world, crowd of patients with variety of illnesses are suffering to get data, past history, consultation, treatment, suggestions etc., and make research difficult in this area. To make this task easier and various methods are used in crowd sourcing technology and this paper deals with the application, methodologies adopted, advantages and disadvantages of the crowd sourcing method in the field of medical research.

Keywords- Crowd Sourcing, Citizen Science, PatientsLikeMe, 23andMe, Genomera, DIY Genomics, Quantified Self

I. INTRODUCTION

Crowdsourced health research studies have come as a natural add-on of the tasks of the health social networks, and that can be researcher-organized or participant-organised. In the past, professional researchers have been crowdsourcing from health social networks for the behaviour of conventional studies. Participants have also started to arrange their own research studies by means of health social networks and health alliance groups created for the purpose of self-experimentation and the enquiry of health-related issues. Crowdsourcing health research studies are the core of three concurrent trends such as Citizen Science, Crowdsourcing and Medicine 2.0 / health. Citizen science concept is the standard of activities that are related to science by the individuals who has no training previously in a specific field. They may include scientists, laypersons or those who are professionalized in another field. The citizen science projects exist in this world over hundreds of years. One of the well-known examples for citizen science the National Audubon Society's annual Christmas bird watch in the year 2011 with thousands of participants[1]. Another important project is Galaxy Zoo. In this project, approximately 250,000 individuals have commented on the astronomical data from the Sloan Digital Sky Survey [2,3]. An another industry group that supports the citizen science is the Citizen Science Alliance [24]. Crowdsourcing is the rehearsal of turning to a group of people to get the needed information, goods and services. The term crowdsourcing is a union of crowds and outsourcing and was coined in the year 2006 by wired magazine author Jeff Howe in the article "The Rise of Crowdsourcing". Crowdsourcing is the execution of ideas, services or information by seeking contribution from a collection people with the help of the Internet. Soliciting vast individuals from an open call simplifies self-selection. There is possibility for crowd sourcing to profit from the input of likely and apt individuals who possess the best ideas and bring together a vast set of skills and backgrounds to carry with the current task. As the term indicates crowdsourcing occurs when an individual or an organisation appeals for specific resource from group of individuals or the crowd. These organisations influence the internet, social media and purpose-built platforms to evoke the knowledge they are seeking. This provides a platform to engross with a wider spectrum of sources and other conventional sources of proficiency through regular paths of arrangement. At present this work is concentrating more on the using crowd source in medicine to improve the health of the individuals so as to store and get the data for future reference.

II. CROWDSOURCING IN MEDICINE 2.0

There are some early discussions of medicine in 2008[4]. They focused on the deployment of social media in a health context. It means that the medicine 2.0/health 2.0 is the use of web tools such as blogs, videos etc., [5] A concept called participatory medicine was introduced to emphasize the active participation of individuals in 2010: "This new definition devised by the board of the Society of Participatory Medicine is a movement in which networked patients shift from being mere passengers to responsible drivers of their health, and in which providers encourage and value them as full partners." [6]

An Internet study found that the US Internet users of 27% had tracked all the health related online and almost 18% had sought to locate others with similar health concerns via the Internet [7]. Social Networks such as Face book, LinkedIn are some of the online communities where the individuals may discuss and share information regarding medical conditions, symptoms, and treatments. [8]They also exemplify the predicted progression of engagement in online communities developing in three stages from Information to:

- 1) Sharing
- 2) Cooperating
- 3) Participating in collaborative action

III. APPLICATION OF CROWDSOURCING IN MEDICAL AND HEALTH RESEARCHES

A. Medical Research Projects

There are several applications of crowdsourcing in medical research [23]. In 2005, a non-profit organisation called PersonalGenomes.com in Harvard Medical School aims to produce, aggregate and interpret human biological scale data on unprecedented scale. This organization allows the individual to share the genome sequence and data for the purpose of medical research all around the world.

Researchers in Perelman Medical School used crowdsourcing to point out as well as record the whereabouts of around 1400 lifesaving AEDs in Philadelphia. Crowdsourcing was used by those researchers in order to execute a search in literature, widely using Quora and Yahoo answers. They helped the researchers to track and review 21 literatures that are related to health.

There are many companies that use crowdsourcing to advance medical science. Apple Inc. is a multinational company that launched open source software called Research Kit. This software allows researchers to create an app that helps to turn the Apple users into the participants of medical research. As there are over millions of people around the world owns an Apple product, the devices like iPhone, iPad are equipped with high processors and powerful sensors that can locate and record the data concerning to measurements, movements and volunteered inputs and makes them a powerful tool in medical research. After launching Research Kit, many numbers of medical institutions are using it and also created apps for collecting data to study diabetes, asthma, breast cancer and cardiovascular disease [25].

B. Health Research Studies

The health research studies using crowd sourcing maybe a combination of both citizen science and crowdsourcing. In crowd sourcing studies, participants are selected online with a website to a large capacity of audience using Internet related techs. These participants can be subjects instead of performing scientific activities, hence would not be taken as citizen scientists that are the demeanour of scientific activities by the participants. Firstly, the crowdsourced research may give chances for more levels of privacy as wells as openness, since the participants are the ones who decide which data to share with whom. Secondly, the rewards within crowd sourced research may result way directly to study the participants along with health communities [9]. And finally, funding that is from different sources (advocacy group, self-funding, etc.).The participants have various types of motivations for joining in health research studies using crowd sourcing. The participants maybe personally attracted due to curiosity in a health area. There is a dimension of broader societal perspective in which the individuals relate themselves to society. Being a citizen scientist, sharing personal information or using the information to access studies could be taken as acts of citizenship [10,11].

IV. METHODS OF HEALTH RESEARCH STUDIES USING CROWDSOURCING

By using the health social network unit, the researchers who are trained by the institutions organizes the Researcher-organized studies. Consider an example; let the studies are organized by Patients LikeMe[12] and 23andMe [13]. Usually the Citizen scientists design and operated the Participant-organized studies. The research methods are explained in detail in Table 1.

Table 1: Research methods in health research studies

RESEARCH METHODS IN HEALTH RESEARCH STUDIES USING CROWDSOURCING		
	Study organizer	Methods of research and data types
Researcher-organized studies	PatientsLikeMe	Self-reported data, survey questionnaires
	23andMe	Genotyping data, survey questionnaires
Participant-organized studies	Genomera, DIY genomics [14], Althea Health	Genotyping data, blood test results, self-reported data, survey questionnaires
	Quantified self [15]	Self-tracking device data, self-reported data

V. RESULTS

At present, the largest operator for crowd sourcing health research studies is PatientsLikeMe. It contains one of the largest registries and online social-networks [16]. The Lithium study is one of the best PLM studies [17]. A member of PLM community convinced other members to join in a participative study. A participative study is nothing but patients applying the published findings [18]. In the beginning of the study, 348 patients started the off-label use of lithium which is overseen by their physicians. And in the

end, 149 patients took lithium for minimum of two months and 78 of the patients took it for a year. But it was observed that the lithium did not have a positive impact on the patients. After that, a study was conducted to observe the patients by comparing the 149 cases with 447 controls based on the progression of disease [19,20]. This feature of patient-organized studies characterizes it as citizen science. The flagship of PatientLikeMe is Amyotrophic Lateral Sclerosis (ALS)- a specific research. A study which was done recently investigated a potential connection between the physical uses of a limb and also a concordance for handedness (not footedness) was found in the limb onset of ALS in 343 patients. This study has observed that because of 1 arm dominating in activities of upper-body but the limbs are used equally in lower-body. Having over 1000 conditions on the platform of PatientsLikeMe, one of the benefits of newly crowd sourced methods is the ability to perform comparative research. A different study took the standardized disease measurement scale for ALS by using questionnaires as a beginning point to improve the detailed measures of a patient function sensitivity in advanced ALS [21,22].

A useful resource called Health Social Networks to investigate an activity related to drug such as side effects, patient sentiment, etc., Off-label drug use is common as physicians may use side effect as main effect. Although, 73% cases lack the scientific evidence for off-label drug use. In health social networks, the large numbers of patients in it can help in a systematic investigation of this issue.

In a study, a positive experience had been reported by 19% of PLM community members in a survey. In another study, in health social networks the benefits to obtain information about disease peers was reported. It includes how well the patients are doing when compared to others.

VI. ADVANTAGES OF MEDICAL RESEARCH USING CROWDSOURCING

- 1) With the help of crowdsourcing, the medical researchers can collect data which requires less time and also cost-effective [23].
- 2) Crowdsourcing can also be used in order to do a particular research in medical field to collect the data, process them and solve it.
- 3) The digital communication and technologies speeds up the researching process. Cloud computing technologies also create a place for individual or a researcher to share and access the database all around the world.
- 4) The main advantages of crowdsourcing is based on reducing the labour requirements, cost, increasing the productivity and creativity, access to the contributions of public.

VII. CONCLUSION

Crowdsourcing has many applications in the field of medical research. Many methods are being used under two broad categories. viz. research organised studies and participant organised studies. For each type two methods were discussed in this paper. Patients LikeMe is the largest operator with more number of registries and online social networks. Results were discussed with results of two specific fields like Lithium study and Amyotrophic Lateral sclerosis. Advantages are discussed with the help of the current literature.

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