



HAL
open science

Lay Crowd-Sourced Expertise (LCE) and its Influence on the New Role Of Patients: Ethical and Societal Issues

Eugenia Lamas, Rodrigo Salinas, Marcela Ferrer, Cédric Bousquet, Dominique Vuillaume

► **To cite this version:**

Eugenia Lamas, Rodrigo Salinas, Marcela Ferrer, Cédric Bousquet, Dominique Vuillaume. Lay Crowd-Sourced Expertise (LCE) and its Influence on the New Role Of Patients: Ethical and Societal Issues. *Exploring Complexity in Health: An Interdisciplinary Systems Approach*, 228, pp.80-4, 2016, 10.3233/978-1-61499-678-1-80 . inserm-01592823

HAL Id: inserm-01592823

<https://inserm.hal.science/inserm-01592823>

Submitted on 25 Sep 2017

HAL is a multi-disciplinary open access archive for the deposit and dissemination of scientific research documents, whether they are published or not. The documents may come from teaching and research institutions in France or abroad, or from public or private research centers.

L'archive ouverte pluridisciplinaire **HAL**, est destinée au dépôt et à la diffusion de documents scientifiques de niveau recherche, publiés ou non, émanant des établissements d'enseignement et de recherche français ou étrangers, des laboratoires publics ou privés.

Lay Crowd-Sourced Expertise (LCE) and Its Influence on the New Role of Patients: Ethical and Societal Issues

Eugenia LAMAS^{a,1}, Rodrigo SALINAS^b, Marcela FERRER^c, Cedric BOUSQUET^{a,d}
and Dominique VUILLAUME^e

^a INSERM U1142, LIMICS, F-75006, Paris, France; Sorbonne Universités, UPMC Université Paris 06, Université Paris 13, Sorbonne Paris Cité, F-93430, Villetaneuse, France.

^b Facultad de Medicina, Universidad de Chile, Santiago, Chile.

^c Facultad de Ciencias Sociales, Universidad de Chile, Santiago, Chile.

^d SSPIM, Department of Public Health and Medical Informatics, CHU University Hospital of Saint Etienne, France.

^e CERMES 3 : INSERM U.988/UMR CNRS 8211/EHESP/Université Paris Descartes, F-94801, Villejuif, France.

Abstract. The emergence of social media on the Internet allows patients to discuss about their chronic diseases within online communities sharing common interests. This allows patients to gather other patients' experience, and gain new knowledge that is usually not shared by healthcare professionals. In this context, further studies are required on the actual impact of the use of social networks on the quality of life of patients participating in these online communities, focusing on the evolving role and impact of Lay Crowdsourced expertise (LCE) in improving disease management and control. We present a study on a large number of posts from social networks of different online communities. This study allowed us to choose four pathologies, with distinctive characteristics relevant for our future analysis, and to define the themes that will be covered in future work by online questionnaires. The analysis of responses from patients, who volunteer to participate, will help us in exploring how interactions between patients, on these online communities, may help them to gain useful information for managing their conditions and improving their quality of life. Furthermore, we will identify new ethical issues that arise in the sharing of health data.

Keywords. Crowdsourcing, Social media, Data protection, Ethics.

1. Introduction

The global trend towards an ever-increasing use of social networks during the last decade has resulted in the creation of plenty of online communities of patients, wishing to make use of the Internet as a platform for identifying other healthcare consumers, with common interests. These online communities are composed mostly by patients suffering chronic conditions having a negative impact on their quality of life, organized

¹ Corresponding Author: eugenia.lamas@inserm.fr

in forums in which they freely interchange views and information concerning personal experiences, opinions and answers, and seek social support [1,2], favoring patients' empowerment [3]. These online discussion forums take advantage of the technological features of the Internet, allowing the easy gathering of a huge amount of information originated in a variety of different sources (crowdsourcing). These forums have allowed the creation of a previously unseen collective knowledge and expertise among patients and their relatives, concerning their conditions, including information on biomedical research and innovation aiming at identifying treatments and palliative care, targeted to alleviate their suffering.

During the Seventies and Eighties, when traditional patients organizations were created around some particular conditions (e.g. orphan diseases, AIDS, autism and other mental diseases), and self-help and support groups multiplied, a new sort of actor was allowed to participate in discussions previously restricted to scientists and physicians, constructing a Lay Expertise that legitimated their arguments as authoritative knowledge, giving value to experiential and commonsensical knowledge [4,5]. The appearance of Internet in the Nineties, and the subsequent development of social media in the last decade, have multiplied the potentialities of patients' communities, giving place to a Lay Crowdsourced Expertise (LCE), nourished by a myriad of simultaneous interactions and free access to real-time updated scientific information. In this context, we consider necessary to implement further studies on the actual impact of the use of social networks on the quality of life of patients participating in these online communities, focusing on the evolving role and impact of LCE in improving disease management and control.

The goal of this article is double: To analyze the content of messages posted by patients in specialized "online communities", and to identify themes that should be explored in future work thanks to a research protocol that will address relevant issues related to patients' use of Internet-based social networks. Since the turn of this century, a number of research reports have been published, evaluating the impact on patients' health of their participation on these online communities, including discussion forums, specialized social networks, and platforms. A qualitative evaluation of communication with Facebook, in patients with Diabetes, was published in 2011, reporting a favorable effect on patients, particularly on the opportunities for receiving direct feedback and emotional support from fellow sufferers, but identifying, also, the presence of explicit promotional activity in more than a quarter of all discussion threads, most of them marketing dietary supplements and natural cures [6]. In 2013, a review was published, examining the available evidence on health outcomes and related effects of using social media, reporting that the outcomes were, in general, favorable -particularly in psychosocial management, with less evidence of benefit for physical parameters- and no adverse events were reported. The authors pointed out the heterogeneity of the identified studies, making difficult a meaningful comparison of their findings, and the covering of a very limited range of social media platforms, dominated by studies of early web-based technology with little consideration of theory surrounding social media. The authors identified, also, a number of methodological flaws affecting the studies included in the review, particularly the use of small samples that diminish the robustness of findings, resulting in substantial gaps in knowledge concerning the actual impact of the use of social networks, on the health outcomes and wellbeing of patients. Larger samples are required, they conclude, to confirm the findings of their review [7].

2. Methodology

2.1. Selection of diseases on a sample of patients' posts

In order to better define the scope of our research, we conducted a preliminary study by performing secondary analysis of patients posts collected within the Vigi4MED project, whose objective is to assess how the existing information available in social networks may complement data sources usually processed in pharmacovigilance [8]. The consortium of the Vigi4MED project has extracted 63 million health-related messages, from 19 social networks in French language, in order to evaluate safety issues related to drugs. As part of the Vigi4MED project an extract of 7 million posts was analyzed by natural language processing tools in order to recognize “named entities” describing pathologies, signs or symptoms. We evaluated this output in order to select four chronic diseases with or without available treatment that fulfill our requirements.

2.2. Identifying themes for our future exploratory-descriptive survey

Since the methodology in our future research protocol will comprise an exploratory-descriptive survey, we analyzed a sample of 120 patients' posts for each selected disease, in order to determine the themes that should be covered by the questionnaire. We decided to address the following three relevant issues, related to patients' use of Internet-based social networks:

- The first aspect to be evaluated is the extent in which this constantly evolving LCE causes an actual improvement in the perceived quality of life of those participating in these social networks health related forums. We aim at evaluating the characteristics and dynamics of the interchanges among patients, and their added value on how they experience their condition.
- The second issue to be explored is online communities members' perception of the ethical aspects involved in sharing personal information during these interchanges, including confidentiality, privacy, data protection and self-conducted research [9].
- The third subject we wish to evaluate is how information is shared in social media, concerning personal experiences with disease and treatments: personal narratives, drugs information, other websites reports, quality, and characteristics of healthcare providers (either institutions or physicians).

3. Results

3.1. Selection of four chronic diseases for our future exploratory survey:

Based on our sample of patients' posts, we observed that when the shared condition falls in the category of “incurable”, the interchange bears a certain dose of pessimism, particularly when the disease is invariably fatal, as it is the case, for example, of Amyotrophic Lateral Sclerosis. When treatment exists, however, even in those cases in which this it is restricted to palliative measures, interchanges are orientated to share information on therapeutic effectiveness and potential treatment-related adverse effects. The posting bear a different tone, also, when they are related to conditions whose

causes are unknown and a psychosomatic origin is supposed, or in diseases to which a social stigma is attached. This analysis allowed us to select four chronic diseases, depending on the availability of treatment and the characteristics of the condition.

- Multiple sclerosis: chronic neurological disorder with available treatment options.
- Amyotrophic lateral sclerosis: chronic neurological disorder with no available treatment.
- Fibromyalgia: chronic allegedly psychosomatic condition.
- Alcoholism: chronic psychiatric disorder with poorly effective treatment options and social stigma attached to it.

3.2. Identification of themes that should be explored in our online questionnaires

Our sample of 120 patients' posts for three of the four selected chronic diseases was extracted from the *Vigi4MED* corpus for: Multiple sclerosis, Amyotrophic lateral sclerosis, and Fibromyalgia. When considering alcoholism, we explored the *baclofen.fr* website, where patients and healthcare professionals discuss about the benefits and risks of using baclofen, traditionally used for the treatment of muscular spasticity, currently being investigated in France for the treatment of alcohol addiction.

We were able to define the major themes that will serve as the basis of the online questionnaires that we will build using an exploratory-descriptive survey.

- Topics present in the interactions with other patients, family and friends
- Emerging influential users and the building of mentoring relationship among the membership of online communities
- Trust building among contributors, and the validation of information supported by their experience
- Feedback mechanisms and their effect on interchanges dynamics
- Patients' experience of their condition and treatments
- Patients' perception of their quality of life
- Patients' perception of the ethical aspects involved in sharing personal information: privacy, data protection and self-conducted research

4. Discussion

We relied on the secondary analysis of a sample of patients' posts collected within the *Vigi4MED* project, which started before the beginning of our study. This allowed us to benefit from the parsing of 7 million health-related messages extracted from 19 social networks. This first step of familiarization with a huge amount of patient's posts has allowed us to identify four chronic diseases presenting a particular interest for our research. In a second step a sample of 120 patient's posts for Multiple sclerosis, Amyotrophic lateral sclerosis and Fibromyalgia were randomly extracted from the *Vigi4MED* corpus, and regarding the alcoholism, we explored the *baclofen.fr* web site. This analysis using a larger amount of samples compared to previous studies, enhanced the robustness of our findings, both regarding the selection of these four disorders and also the themes that will be the bases for the online questionnaires. Then, these results allowed us to build foundations for a future survey whose purpose is to allow a better understanding of the constantly evolving LCE, as a key component of the new role of

Internet based organizations of patients. An online questionnaire will be applied in future work to a non-probabilistic sample of active participants of social networks, including a French patients social media (Carenity), a Chilean patients community, and Patients Like Me (PLM), from USA. The questionnaire will be sent to all participants of the online communities under study. Responding participants will be self-selected. The online questionnaire will be composed by both open and open-ended questions covering the themes described in the results section.

This research will permit a better understanding of how LCE may collide with the professional approach of health and disease, traditionally commanded by physicians and biomedical researchers. This survey will help identifying the main differences in the interchanges among patients suffering the four selected conditions, and how these differences relate with their distinctive features. We will also analyze the perception by members of these communities of the new ethical issues arising from these social health networks. These new issues, not included in the current ethical, legal, and policy analysis, are similar to those identified in our previous report on Patient Led Research (PLR) [10].

Acknowledgments

The authors acknowledge the contributions of Bissan Audeh who collected content from social media, and François Morlane Hondère who selected a sample of relevant patients' posts about the selected topics (supported by the grant AAP-2013-052 from the ANSM, the French agency for drug safety through the Vigi4MED research project).

References

- [1] A.Y.S. Lau, T.M.Y. Kwok, Social Features in Online Communities for Healthcare Consumers – A Review, in *Online Communities and Social Computing*, A.A. Ozok & P. Zaphiris (eds.), Springer-Verlag, Berlin-Heidelberg, 2009, 682-689.
- [2] P. Wicks, M. Massagli, J. Frost, C. Brownstein, S. Okun, T. Vaughan, R. Bradley, J. Heywood, Sharing Health Data for Better Outcomes on PatientsLikeMe, *Journal of Medical Internet Research*, **12.2**, (2010), e19.
- [3] M. Househ, Empowering patients through social media: The benefits and challenges, *Health Informatics Journal*, **20.1** (2014), 50-58.
- [4] T. Borkman, Experiential Knowledge: A New Concept for the Analysis of Self-Help Groups, *Social Services Review*, **50** (1976), 445-456.
- [5] S. Epstein, The Construction of Lay Expertise: AIDS Activism and the Forging of Credibility in the Reform of Clinical Trials, *Sci Technol Human Values*, **20** (1995), 408-437.
- [6] J.A. Greene, N.K. Choudhry, E. Kilabuk, W. H. Shrank, Online Social Networking by Patients with Diabetes: A Qualitative Evaluation of Communication with Facebook, *Journal of General Internal Medicine*, **26.3** (2011), 287-292.
- [7] M. Merolli, K. Gray, F. Martin-Sanchez, Health outcomes and related effects of using social media in chronic disease management: A literature review and analysis of affordances, *Journal of Biomedical Informatics*, **46.6**, (2013), 957-969.
- [8] <http://vigi4med.com/>
- [9] M. Househ, Sharing Sensitive Personal Health Information through Facebook: the Unintended Consequences, *Studies in health technology and informatics*, **169** (2010), 616-620.
- [10] E. Lamas, R. Salinas, D. Vuillaume, A new challenge to Research Ethics: Patients-Led Research (PLR) and the role of Internet based social networks, *Special Topic Conference 2016 of the European Federation for Medical Informatics. "Transforming Healthcare with the Internet of Things"* (April 17-19, 2016)