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GIENS WORKSHOPS 2016/SOCIETAL PHARMACOLOGY

Advantages and limitations of online communities of patients for research on health products[☆]

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Summary The way patients and their caregivers share information on various online platforms about health topics and their own experiential knowledge presents new potential environments for research, particularly as concerns health products. The information provided individually and voluntarily by patients who are members of these online communities is a new resource for identifying and understanding precisely how health products are used, assessing their effectiveness, quantifying potential adverse effects in real-life situations, detecting subtle signs that are significant for experts in pharmacovigilance and addiction studies, and developing new assessment tools to help form new working hypotheses. How patients freely express their experiences and feelings and the reality of what they share also opens the way for societal research into health products, a field that is still under-explored. Well-established regulations govern research into health products, which uses resources and methodologies that have changed little over the years. However, the development of online communities of patients presents new possibilities in this field. The challenge we face today is defining their place among traditional research techniques. This place cannot be accepted by all stakeholders unless we first establish a firm understanding of the advantages, limitations, and constraints of these communities. The round table on this topic endeavoured to: explore these issues and develop a better understanding of the phenomenon and the different varieties of online communities and networks for patients; identify possible advantages, special features, and methodological, regulatory, and ethical limitations that researchers currently face; and finally, to put forward the first recommendations in this growing field of research.

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Abbreviations

ALP	automatic language processing
ANSM	<i>Agence nationale de sécurité du médicament et des produits de santé</i> (French Agency for the Safety of Medicinal and Health Products)
IRB	institutional review board
FMTI	French multi-terminology indexer
MedDRA	medical dictionary for regulatory activities
PRO/PRI	patient-reported outcomes/patient-reported information
SMTS	<i>serveur multi-terminologies en santé</i> (multi technology health server)
SNOMED	systematic nomenclature medical clinical terms
UMLF	unified medical lexicon for French
UMLS	unified medical language system

Introduction

Internet users have appropriated new features of the web, creating what is referred to as Web 2.0, which provides more opportunities for interactions and information sharing. In recent years, this development has led to the emergence of different social systems, including social networks, blogs, wiki pages, and interactive community platforms. Health, a daily preoccupation for many, rapidly became one of the preferred topics for internet users surfing these sites, showing how willing individuals were to become actors in their own medical care. The internet is an easy-to-use tool offering numerous possibilities, from conducting simple searches

for information to actively participating in building up our knowledge of a condition by sharing personal experiences, thereby encouraging patients and their caregivers to reach out and become sources of information themselves. The round table on this developing current topic set the following goals: clarifying the different types of online patient systems or communities identifiable on the internet; understanding the special features of each type; and considering the possibilities, advantages, and limitations of how these media and the resulting data could be useful and valuable for research and for creating research partnerships. This discussion was conducted with an understanding that it overlapped in some aspects with the topics covered by another round table in 2015 including data accessibility and ownership and more generally issues relating to data warehouses, patient databases, big data, and open data [1]. Furthermore, the continual creativity of users, their role in assessing health solutions, digital technological advancements, and innovations in telemedicine, e-health, artificial intelligence, and connected objects will continue to add to and improve these discussions.

Members of the round table also attempted to draw on their varied professional experience (from working as consultants, clinicians, clinical research managers, pharmacoepidemiologists, health product manufacturers and from working with patient associations and marketing platforms, etc.) as well as analysis of available literature to reveal certain key factors that online patient communities bring to research. The goal of these efforts is to propose recommendations that can act as a reference for all operators in this field and in the research community.

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