

Social Media in Science and Medicine

Tools for Scientific Networking

To friend or not? This is the *status quo* in social media. But can this be applied to specific fields such as life sciences and medicine?

Introduction

The ability to collect information of individuals in online media has revolutionized the way researchers explore human society [1]. Social systems can be seen as a nonlinear superposition of a multitude of complex social networks where the nodes represent individuals and the links between them capture the variety of different social interactions [1]. With more than 700 million Facebook members and more than 200 million Twitter users giving opinions on products, there is an increasing number of companies utilizing social networks to reach consumers [2]. In addition, in the Web 2.0 era, blogs for discussions, podcasts, and the emergence of different types of social media "services" (i.e.: LinkedIn, Meet-Up, Anianet, etc) to connect people have helped the exchange of information in a variety of fields. In life sciences, social networks are already improving market research, physician relations, patient relations, clinical trial evaluation and medical education. Understanding how companies, especially in the pharmaceutical and biotechnology sectors, can utilize social networks will be paramount to facilitate the achievement of higher productivity in these sectors. Recent reports have shown that life sciences companies have already started to use social networks effectively to interact with external communities and collect important data [3].

These new tools in the web are becoming powerful platforms that will have the potential to help accelerate the diagnosis of new and undiagnosed diseases, evaluate new treatments and facilitate information exchange between healthcare professionals and patients. Last year, the National Institutes of Health (NIH) issued a funding opportunity for scientists studying how to improve public health through social networks. However, there is still some concern on regulations, especially when dealing with patient data. A recent survey demonstrated that 65% of the life sciences companies plan to adopt social networks on a daily basis, but one

third do not have plans to use it in any capacity, mainly because of regulatory uncertainty [4]. Even with lack of regulatory clarity as the largest barrier, a trend towards social networks and the use of social media for clinical studies by pharmaceutical companies, information exchange between physicians and scientists and other applications in life sciences are starting to become a reality. The same way social media is now part of our daily life, we believe that it could become an essential tool for life sciences.

The Impact of Social Networks in Science

Science is a word from the Latin for "knowledge", and it is defined as a systematic enterprise that builds and organizes knowledge in the form of testable explanations and predictions about the world through collaboration. However, the main purpose of contemporary science is the achievement of specific goals by individuals using independent resources to publish articles and receive funding. Modern science is very competitive, and in the long run the knowledge we accumulate is relatively small compared to a model of scientific collaboration with the idea of sharing information. These new trends in social media can be applied to science and thereby help society reach levels of knowledge that are extraordinary. In fact, there is one social community that was launched recently and is growing fast named ReserchGate (see Table 1). This social media community already has more than 1 mil-



Marcelo P. Coutinho, DataGenno Interactive Research Ltd., Itaperuna, Genetics Department, Federal University of Rio de Janeiro (UFRJ), Rio de Janeiro, Brazil



Fabricio F. Costa, DataGenno Interactive Research Ltd., Itaperuna, Rio de Janeiro, Brazil; Cancer Biology and Epigenomics Program, Children's Memorial Research Center and Northwestern University's Feinberg School of Medicine, Chicago, IL, USA

lion members that have a profile webpage, sharing information about specific fields of their interest and also creating groups of discussion. ResearchGate has been called the Facebook of Science. Some of the features offered include sharing articles and also accessibility to a variety of peer-reviewed papers. Importantly, members of this community that have similar scientific in-



terests can start collaborations. This is an example of social media that can improve and expand knowledge by connecting researchers from the same field globally. However, more specific regulation, mainly regarding sharing patient and sample information data for research, will be needed.

Social Networks in Medicine – Patient x Physician

Rapid communication between individual researchers and physicians across continents will allow global exchange of ideas, tools and technologies (5). People, especially patients, are individual data stores, and as online social networks

link all of them, people can become part of the dynamic data warehouse. Social networks can be faster, cheaper and better data sources than any traditional way of gathering information such as registries, research panels and static databases. Examples of social media websites that are networks for information exchange between healthcare professionals include Sermo and Ozmosis (see Table 1 for all examples), and they can facilitate access to physicians' knowledge about current medical practices, decreasing the power of traditional market research. Patient networks such as Inspire and PatientsLikeMe are rich sources of patients' insights and clinical data. In the case of PatientsLikeMe, a recent report has shown how social networks of patients are also able to accelerate clinical discovery for specific diseases (this study used data from patients diagnosed with Amyotrophic Lateral Sclerosis) [3]. In fact, social networks can generate epidemiological and clinical data sets that were previously dispersed between physicians' charts, Electronic Medical Records (EMRs) and oral clinical histories.

Data from social networks may also be more inclusive than any traditional source. One example is MediGuard, an online social network of 2 million people around the world who receive medication alerts and comments about their prescription drugs (also see Table 1). Another example, SpineConnect, is a social network of surgeons that provides an online learning environment for experts bridging geography. This type of tool can also improve the adoption of new and more efficient products by these professionals. Interestingly, web-based studies by cloud computing have been used to identify novel phenotype-genotype associations with data from consumers of predictive genetic tests [6]. This could also be a new way to pursue association studies in genomics. Finally, with the increased number of patent expirations and fewer pipelines for drug discovery, online social networks could provide access to new ideas, product concepts, innovations, research novelties and new drugs for pharmaceutical and biotechnology companies [2].

Developing Better Tools for Networking in Science and Medicine

Both academic and private sectors are in need of user-friendly and efficient tools for information exchange. Pharmaceutical companies have interdepartmental databases of patients and samples for clinical trials and for patient follow-up; however there is no communication between these databases, including databases housed within the same company. In addition, to date, there is no social media in the market that offers useful solutions for medicine and science in the clinical genetics field. It is paramount for physicians to have reliable tools that will facilitate diagnosis and identify treatments that are more efficient. As in the medical field, there is an increasing need for solutions in the scientific field



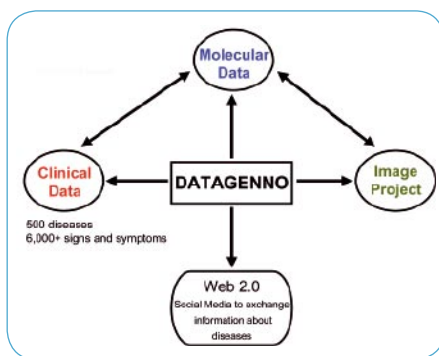


Fig. 1: DataGenno is a social media solution for the study and diagnosis of different genetic diseases. The portal has clinical data, molecular genetics data and a library of pictures for all signs and symptoms of groups of genetic diseases. The database has already 500 diseases and approximately 6,000 signs and symptoms. DataGenno has also a search engine feature in which the users will be able to type keywords for different signs/symptoms and also diseases. Genetic features are connected to the interactive search and the user will be able to explore and exchange information through a variety of social media tools.

for networking and communication between professionals with common interests (ResearchGate is already providing some tools to achieve this goal). Even though science is all about competition and who publishes data first, we believe that the best way for science to have a major impact in society and change the way we ap-

proach diseases is through collaboration and networking. In the end, the outcome will be the development of better drugs and faster translation of basic science to medicine. Following this trend, we have developed a portal – DataGenno – with the objective of providing a web space for healthcare professionals, scientists, and even patients, to exchange information about genetic diseases [7].

DataGenno has four main features: 1) a search engine for differential diagnosis of diseases with clinical and molecular data compiled in a database (mostly genetic diseases and chromosomal abnormalities); 2) a personal service for groups and/or institutions that want to build databases of patients and/or samples; 3) images for every sign and symptom of diseases in the database that we have constructed and 4) a webpage or user profile as a Web 2.0 interface to facilitate the communication and networking between professionals (for details see Figure 1).

There are numerous features that differentiate DataGenno from the sites that are currently available. Our portal has a growing database with patient and disease information, a search engine for differential diagnosis and features for information exchange between professionals and patients (i.e.: messaging capabilities). It is also the first portal that provides a strong connection between clinical and molecular genetics. This link is a feature of interest since human genomes are sequenced both faster and at a lower cost [8]. We believe that our tools will enable the exchange of DNA sequencing information in the near future, and that the use of the platform will integrate three applications that are of value to social networks: information collection (main-

ly from patients and samples), communication between users and collaboration, with the formation of groups of discussion to facilitate disease diagnosis and treatment. Our platform will be mainly targeted to physicians, scientists, physician scientists, genetic counselors and other professionals that have interests in diseases with a genetic or genomic component.

Conclusions and Future Directions

We believe that social media networks will have increased value in the scientific community; the life sciences industry needs information from people (patients in this case), people need information from these companies and the life sciences industry also need to collaborate outside their walls. As regulatory clarity emerges and more companies adopt social media tools, these technologies have the potential to revolutionize healthcare, clinical trials and research the same way they have revolutionized human society. Developing solutions to allow better information sharing will add value to the life sciences community. We believe that we have created a platform that addresses this need; DataGenno will be an important tool for the diagnosis of rare genetic diseases, with the potential to become a novel component in social media applied to science and medicine.

References

- [1] Szell M. *et al.*: Proc Natl Acad Sci U S A.107 (31): 13636–13641 (2010)
- [2] Hisey R.T. *et al.*: Deloitte Research Study (2010)
- [3] Wicks P. *et al.*: Nat Biotechnol. 29 (5): 411–414 (2011)
- [4] Deloitte: Life Sciences Professionals Social Networks Survey Findings, July 2010
- [5] Bailey DS and Zanders ED. Drug Discov Today. 13 (19–20): 863–868 (2008)
- [6] Eriksson N. *et al.*: PLoS Genet. 6(6): e1000993 (2010)
- [7] Costa FF. *et al.*: The Application of Clinical Genetics. Vol 4: 45–54 (2011)
- [8] Green ED and Guyer MS.: Nature. 470 (7333): 204–213 (2011)

Authors

Marcelo P. Coutinho, DataGenno Interactive Research Ltd., Itaperuna, Genetics Department, Federal University of Rio de Janeiro (UFRJ), Rio de Janeiro, Brazil; **Fabricao F. Costa**, DataGenno Interactive Research Ltd., Itaperuna, Rio de Janeiro, Brazil; **Cancer Biology and Epigenomics Program, Children's Memorial Research Center and Northwestern University's Feinberg School of Medicine, Chicago, IL, USA**

Contact

Fabricao F. Costa, PhD
Children's Memorial Research Center and Northwestern University and
DataGenno Interactive Research Ltd.
fcosta@datagenno.com

Table 1: Some examples of social media that provide solutions in life sciences and medicine.

Social Network	Description	Website
Sermo	Sermo is an online network for physicians with panel discussions about specific topics.	www.sermo.com
PatientsLikeMe	PatientsLikeMe is a website for patients that suffer from the same conditions to share their experiences, progress and get input from others in their network.	www.patientslikeme.com
MediGuard	MediGuard is a patient/consumer network that helps patients to track their medication and exchange information with others.	www.mediguard.org
SpineConnect	SpineConnect is a network of neurosurgeons for panel discussion about cases.	www.spineconnect.com
Ozmosis	Ozmosis is a provider of solutions for physicians to share their knowledge and clinical experiences with each other.	www.ozmosis.com
Inspire	Inspire is a diverse community of patients that can share information about several different conditions.	www.inspire.com
ResearchGate	ResearchGate is a social media for scientists in a variety of fields to exchange information and collaborate.	www.researchgate.net
DataGenno*	Datagenno is an interactive database containing molecular and clinical genetic information for healthcare professionals, research scientists and patients.	www.datagenno.com

*The social media that will be the missing link between molecular and clinical genetics for healthcare professionals, physicians and scientists.