

# Let's get real about virtual: online health is here to stay

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(Received 10 June 2013; accepted 10 June 2013; first published online 1 August 2013)

## Summary

A lot has been written about the opportunities of the Internet for medicine, and lately, also for disease research specifically. Although it remains to be seen how significant and sustainable a change this will result in, some recent developments are highly relevant for the area of genetic research. User-friendly, low-threshold web-based tools do not only provide information to patients and other users, but they also supply user-generated data that can be utilized by both medical practice and medical research. Many of these developments have been below the radar of mainstream academic research so far. Issues related to data quality and standardization, as well as data protection and privacy, still need to be addressed. Dismissing these platforms as fads of a tiny privileged minority risks missing the opportunity to have our say in these debates.

## 1. Editorial

Most of us have become used to hearing (or singing) the praise of the great opportunities that the Internet entails for medicine. In the past few years, books and commentaries have credited the Internet with the 'creative destruction of medicine' (Topol, 2012), with revolutionizing medical training (Ruiz *et al.*, 2006), and with helping to 'reinvent discovery' (Nielsen, 2011), to name just a few examples.

Regardless of whether or not we agree that the Internet has the potential to truly 'revolutionize' medicine, the increasing user-friendliness, and the interactive nature, of web-based tools in the health domain is remarkable. Until the second half of the last decade, patients used the web primarily to obtain information about health and disease. Also ethical and regulatory debates at that time focused mostly on how to protect patients from incorrect or misleading information (see also Fuchs *et al.*, 2012). Today, although web-based platforms and services in the health domain still provide information, they do much more.

A brief look at two different platforms, *PatientsLikeMe* and *CureTogether*, illustrates this. The first platform, *PatientsLikeMe* (patientslikeme.com), started out in 2004 as a user-driven support network for patients. Patients used it to obtain useful information about relevant research, or new clinical trials and

treatments, and as a platform for mutual support. Almost 10 years and over a hundred thousand members later, it is still free for patients to use, but it has turned into a 'not just for profit' enterprise that makes money by selling patient data to companies and other partners.

The second platform, *CureTogether* (curetogether.com), was founded by two pioneers of the self-tracking movement, Alexandra Carmichael and Daniel Reda, in 2008. *CureTogether* encourages users to quantify and share information about the nature and severity of symptoms, as well as on different treatments they have tried and how they responded to them. The site then aggregates and analyses these (anonymized) data, so that users can see what treatments work for people who are similar to them in terms of symptoms, co-morbidities or demographic parameters. In 2012, *CureTogether* was acquired by the personal genome testing service *23andMe* (23andme.com); the site now encourages users to upload their genetic profiles as well. When sufficient numbers of users have done so, genetic similarities may become an additional reference point in potential searches for 'similar' users.

What these examples illustrate is that the Internet's main role in the health domain has ceased to be that of information provision: contemporary web-based platforms and services integrate information provision and data collection by encouraging patients

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and citizens to contribute data and information about themselves. Internet governance experts Viktor Mayer-Schönberger & Kenneth Cukier (2013) use the term ‘datafication’ to signify the phenomenon that information that was previously seen as irrelevant to any sort of systematic analysis has now become relevant. In the domain of health and medicine, virtually anything that plays a role in people’s lives could potentially aide research or medical decision making (e.g. by providing data for deep phenotyping, information on lifestyle, diet, mood changes, etc.).

A growing body of literature is drawing attention to some of the unintended consequences of this development for users: although some platforms, including *PatientsLikeMe*, place great emphasis on being very open about what they do with the data that users share on their website (*PatientsLikeMe*, 2013), in the case of other services, it is often not immediately apparent for users how their data will be processed and utilized. Similarly, some people may be unaware that by using these platforms, they are creating value for others, often including commercial enterprises. The recent case about personal genome testing company *23andMe*, who faced complaints about allegedly filing for patents behind their users backs (these discussions are summarized and discussed by Rimmer, 2012; Sterckx & Cockbain, in press), exemplifies the complexities inherent in this. What most critics held against the company was not the fact that they filed for patents in the first place, but that the company allegedly ‘hid’ this information in the small print of their terms of service. An enterprise that makes heavy use of the open science and citizen science rhetoric, it was felt, should be equally open about their intellectual property strategy (Prainsack, in press).

However, if web-based services and platforms evolve in a manner that makes it transparent to users how their data will be used, and if issues of data standards and quality are addressed fruitfully, these platforms can indeed play an important role in providing data for medical decision making and research (NAS, 2011; ESF, 2012). In any event, these platforms can no longer be easily dismissed as a fad attractive only to a small elite of the healthy and wealthy. While this view may have held true for early ages of Internet use, several developments in the past few years have changed the game. The availability of portable devices equipped with touch screens, for example, has lowered the threshold for use: people no longer need to be able to start a computer program, or to operate a keyboard, to use these platforms. (Many of us may indeed know stories of elderly relatives or friends who used the Internet for the first time when they were given a tablet computer to speak to their grandchildren through

videophone.) Second, the widespread use of inexpensive battery-powered devices increases the range of Internet users also in countries where stable power supply is an issue (for a critical discussion of this issue, see Napoli & Obar, 2013).

That access to web-based tools in the health domain is no longer limited to a narrow elite does not imply, however, that everybody will use them. As the groups of users are widening and diversifying, so are the reasons for non-use. The reasons for use and non-use, however, are no longer linked mainly to opportunity to access, but instead to concerns about privacy, utility and cost-effectiveness (is the time or effort spent worth what we get out of it?), and the ability to control their own data if users wish to do so.

Patients using these platforms and services frequently engage with medicine in a manner that integrates diagnosis, treatment and research. The new opportunities that such web-based platforms provide for genetics research have been below the radar of many professionals in the field so far. Maximizing their potential will require a solid understanding of how people engage with these sites, what they consider advantages and disadvantages, and how issues of data standards and quality can be addressed (preferably at the point of data input). Either way, online data collection in the health domain is here to stay. If academic research does not take this seriously, commercial companies alone will have determined the terms of the game by the time we are ready to get involved.

I am grateful to Jeantine Lunshof, Shiri Shkedi-Rafid and Tim Spector for helpful comments on this manuscript.

### Statement of interest

No conflict of interest.

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