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I SEARCH, THEREFORE I KNOW NOT

People are trusting scientific expertise less and less, and increasingly rely on what can euphemistically referred to as the "wisdom of the crowds." What are the effects of this, and what might be done about it?

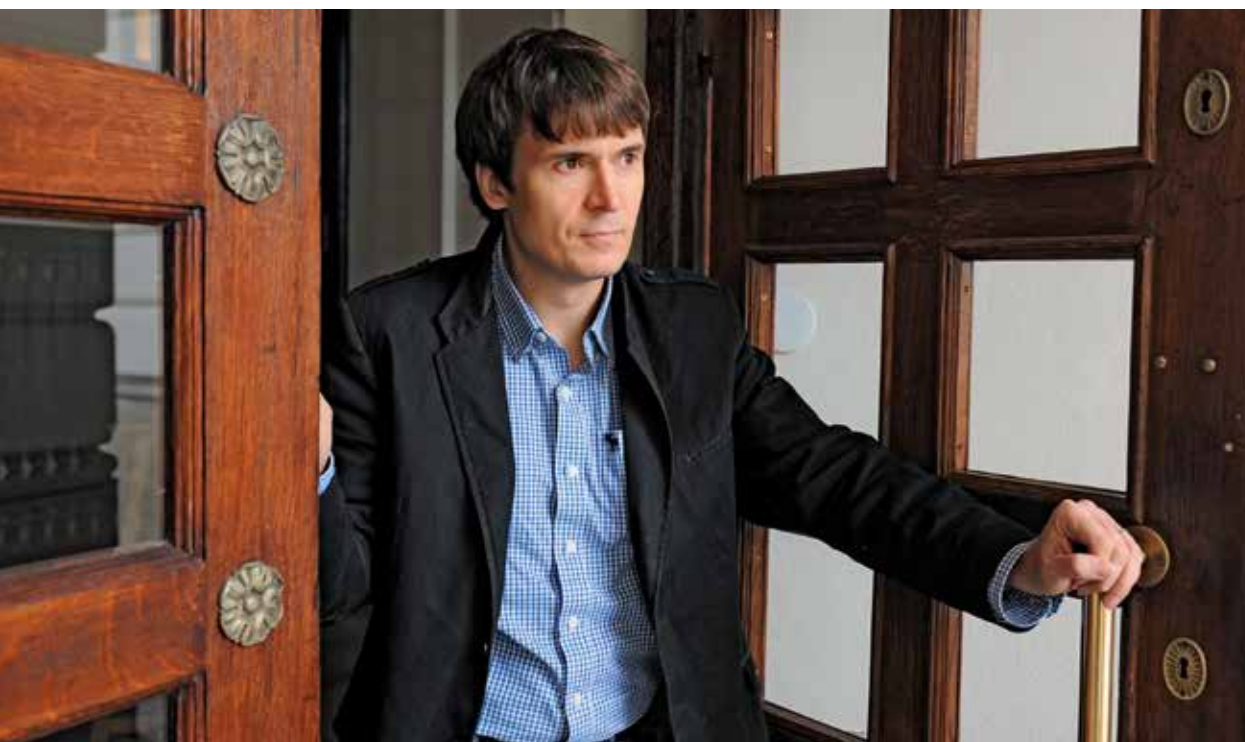
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The phenomenon referred to as "citizen science", whereby groups of non-specialists process scientific knowledge on their own, has been growing in popularity around the world. There are myriad examples, as diverse as Wikipedia or the anti-smog movement in Poland, for instance. At the same time,



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we can observe the growing popularity of anti-science movements, especially ones that call into question the advances of contemporary medicine. While the former phenomenon is undoubtedly beneficial for society, the distrust towards science and scientists is clearly dangerous.

In this latter case, online communities emerge, popularizing the content generated by their own members. They are challenging the scientific discourse on such issues as health, medicine, and nutrition, and promoting alternative, scientifically unfounded notions instead. This is especially visible in movements against genetically modified food, or against shale gas mining, and – above all – against vaccinations.

Lack of trust in healthcare

The less efficiently a country's health services operate, the less public trust they enjoy. Poland's chronically underfunded healthcare system, for instance, is therefore a perfect breeding ground for sentiments that feed into various anti-science and pseudo-medical movements. Aversion to doctors and to medical science in general has been fanned by the long waiting times for doctor appointments in Poland (for example, 13 months for a pediatric endocrinologist appointment in the Łódzkie Province). Other factors that play a role include the paternalistic attitude often shown towards patients on the one hand and their growing expectations on the other. All these issues create a tension in the doctor-patient relationship, which is reflected in the growing number of lawsuits against medical

practitioners. While we have no precise figures on this issue, we can infer certain conclusions from the fact that the number of complaints filed with the Commissioner for Patients' Rights rose from 28,000 in 2010 to 71,000 in 2015. Although there are no accurate statistics as to the share of complaints that related to medical errors resulting in death or injury, the media and popular culture thrive on sensational reports of errors made by doctors and the lack of their accountability. For example, an analysis of hospital records in North Carolina in the United States showed that 0.6% of hospitalizations ended in death, 63% of which were caused by suspected errors in procedures. An extrapolation from these findings performed by Makary & Daniel suggested that medical errors might in fact be the third leading cause of death in the whole of the United States, after cardiovascular disease and cancer. Such findings translate into growing mistrust in the medical community and result in proposed treatment methods being more frequently called into question.

In a partnership-based model of the doctor-patient relationship, the doctor and the patient discuss the choice of optimum treatment along with the potential benefits and risks and decide together which path of therapy to embark upon. Increasing patient involvement in the decision-making process was proposed in the United States as early as in the 1980s. Back then, two important conditions were identified as being critical for the introduction of such a model of medicine: communicating difficult messages using a language free of professional jargon, and providing enough time for the discussion of issues that are important and con-

Demonstration in support
of the Polish medical
community in the city
of Łódź, 29 October 2017

ceptually difficult for patients. According to the reimbursement rules applied by Poland's National Health Fund (NFZ), however, the average length of a consultation with a specialist in Poland is a maximum of 30 minutes (unfortunately, this is often much less in practice), which includes the time needed to conduct a physical examination, analyze additional test results, fill in documents, and communicate recommendations. It is therefore difficult if not impossible to find sufficient time to discuss and explain the clinical nuances of what is often a very complicated situation.

Negative opinions on healthcare therefore feed into various types of anti-science movements and pseudo-medical, scientifically ungrounded treatment methods. The propagation of such content is a manifestation of a broader questioning of the traditional system of knowledge and social order. The communities that generate such content operate based on open collaboration between many individuals who do not know one another yet work together, forming a kind of decentralized self-regulatory organization. Such organizations allow members to join and leave freely, in addition to being highly informal, having a flat organizational structure, and lacking a uniform decision-making center. In his book *The Cathedral and the Bazaar*, Eric S. Raymond suggests that such communities resemble a chaotically managed bazaar, as opposed to the hierarchically coordinated design of a cathedral. In addition, they make use of new, poorly-studied ways of managing large groups of people.

Meanwhile, public trust in medicine and science in general carries enormous social importance and has enormous practical dimensions. Suffice it to say that the introduction of commonly available vaccinations has prevented tens of millions of deaths worldwide. According to estimates, smallpox alone caused three times more deaths in the twentieth century than armed conflicts. However, opposition to science and efforts to question its achievements represent a very lucrative market: for example, \$60 billion worth of dietetic products, not supported by any kind of tests whatsoever, are sold every year in the United States alone. With no effective mechanism for strengthening science and medicine outreach toward the general public, the situation can only worsen, thus impacting negatively on the quality of treatment and the health status of the population.

The age of no knowledge

Amidst the constant struggle over the formal position of various professions, such steps may result in the arrival of a new dark age and the contestation of the hierarchical system of knowledge production and dissemination. The consequences of the emergence of a digital society include growing mistrust of “expert knowledge” and a simultaneous rise in the importance



of “crowd wisdom.” The results can be seen not only in the world of science: it is enough to look at the phenomenon of WikiLeaks and the support enjoyed by Edward Snowden, who disclosed a large amount of classified information, to notice that Western societies are increasingly demanding access to information and its non-hierarchical and transparent distribution. In addition, we can observe growing interest in non-hierarchical models of creating authority and developing knowledge in opposition to university-based, formal knowledge. Such a trend is additionally consistent with a further drop in trust in professional and institutional authorities and with the development of informal meritocracies, typical of the knowledge-based economy.

All these factors are increasingly prompting patients to search for answers on their own, venturing out into the publicly available and unmoderated bazaar of information sometimes referred to as “Doctor Google.” According to figures from 2015, at least one in 20 searches on Google were related to health problems. According to the US National Science Foundation, over 60% of the Americans cite the Internet and online communities as their primary source of information about science, while only 12% make use of the online versions of the traditional media. In the European Union, 67.5% use the Internet on a regular basis and 54% seek information about issues related to health and general knowledge. Such percentages are surprisingly large, particularly if we take into account the complex nature of health issues and the high qualifications needed to effectively navigate medical topics. Nevertheless, people generally prefer to self-diagnose online. This results in a radical change in the way in which patients consume information about health and medicine, with a growing number of patients seeking information on the Internet even before consulting a specialist. In a growing number of cases, “Doctor Google” is assuming the role of a primary-care phy-

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sician triaging patients and enabling them to make quasi-informed health-related decisions.

Life in the global village now means that we not only function within local communities with which we share experiences and which we trust, but increasingly also yield to the influence of strangers who often live on the other side of the world. But importantly, the need for awareness of the sources of knowledge is nonetheless very strong. At the same time, trust in true doctors is on the decline.

Interestingly, the challenging of medical knowledge sometimes does bring good results, for example in cases of very rare diseases, when doctors may not stay abreast of the latest advances in medicine. Also, there are known examples of patients and their families collaborating on carrying out clinical studies, in which they turn from passive participants in medicine into active partners. Introducing a partnership-based model of patient involvement in the therapeutic process requires patients to devote a substantial amount of time, have an adequate amount of basic knowledge, and be willing to constantly update it.

Unfortunately, the urgency of the situation caused by a disease does nothing to help patients, additionally burdened by what is largely a subjective assessment of their own health, to seek out detailed and reliable medical knowledge. The typically brief nature of information found on the Internet, the absence of effective mechanisms for monitoring such content, and the illusory link between popularity and quality all contribute to the quick formation of an “expert opinion” based on a cursory browse through several most frequently visited pages. The illusory impression of specialist knowledge is supported by targeted searches that confirm the first random diagnosis made by the patient, which results in a mistaken interpretation of hastily acquired specialist knowledge about a multifaceted medical problem. An opinion formed in this way, backed by low-quality information, is then presented to a doctor. By objecting to the arguments cited by the patient or openly identifying errors in the patient’s reasoning, the doctor ends up antagonizing the patient, thus inadvertently reinforcing the popular myth of the professional concealment of miraculous treatment methods only “revealed” on the Internet. This fosters belief in conspiracy theories, the conviction that the inconvenient truth may be kept hidden from the public. Mechanisms of searching for information on the Internet also favor the popularization of myths and pseudo-theories by promoting fake news-laden sites and mixing advertisements with actual information sources.

Treatment without a doctor

The mechanisms by which information spreads on social media, undermining medical authorities and promoting conspiracy theories, are deliberately uti-

lized by anti-science and pseudo-medical communities. These groups promote their own, ineffective and dangerous treatment methods by popularizing their own concepts and pursuing active marketing strategies that appeal to those who strive to improve their situation or are disappointed with the possibilities offered by healthcare systems or their speed of action. This pushes more and more patients into the sphere of influence of anti-science communities, for example anti-vaccination movements, which believe that the scientific discourse imposes a hegemonic vision of the world. Often disappointed with real and imaginary failures of science and medicine, they doubt scientific authorities, which coincides with the collapse of confidence in objectivity and scientific methodology. A fear of the logic of capitalism and the pursuit of profit on the part of the Big Industries (Big Pharma, Big Food, and Big Oil) increases distrust in scientists. This provokes a need to seek alternative authorities, among both people who simply interpret existing study results differently, and those who offer theories that are not borne out by any studies at all.

Since the fight against self-diagnosis is doomed to fail, medicine is left to reckon with the inevitable need to provide patients with better and more reliable tools that allow better self-diagnosis. A study conducted in the United Kingdom showed that while standardized “symptom-checker” questionnaires failed to provide correct diagnoses (34% of correct diagnoses), they often did correctly categorize patients depending on the urgency of the condition (80% of correctly identified cases that required emergent medical care). At the same time, the use of online tools that allow cancer patients to receive support, showed that the ability to interact with healthcare workers in the form of an online chat reduced the severity of the stress related to the disease. This means that communication methods, if well harnessed by healthcare providers, can indeed be effective tools for supporting diagnostics and treatment.

Such measures, supported by the technologies of effective information management, will allow patients to become real, modern partners for doctors on the road to the right diagnosis, treatment, and necessary emotional support in difficult periods. Such a model can only succeed if both sides can listen to each other, which is only possible if they have reliable information – both personal expertise gained in the course of long years of medical education, and reliable and trustworthy sources of medical information. Without the support of content-positioning technologies that prioritize not only popularity but also the quality of medical information, however, this utopian vision stands no chance of becoming a reality.

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