The first generation of e-patients

These new medical colleagues could provide sustainable healthcare solutions

For many citizens of most developed countries, the internet has become a powerful and familiar healthcare tool.1–3 About half of adults in the United States have looked for health information on the net, making this the third most popular online activity.1 E-patients (we include both those who seek online guidance for their own ailments and the friends and family members who go online on their behalf) report two effects of their online health research—“better health information and services, and different (but not always better) relationships with their doctors.”2 Based on our own observations, the expert opinions of colleagues, a variety of e-patient and provider surveys, and a few more rigorous trials, we offer five tentative conclusions regarding the emerging world of the e-patient.

Firstly, many clinicians have underestimated the benefits and overestimated the risks of online health resources for patients. We agree with Eysenbach that many medical researchers have become so “distracted by focusing on the negative aspects of the internet” that they have overlooked the benefits it provides.4 Reports of patients coming to harm as the result of online advice are rare, whereas accounts of those who have obtained better care, averted medical mistakes, or saved their own lives are common.5,6 Many e-patients say that the medical information and guidance they can find online is more complete and useful than what they receive from their clinicians.5,6

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Secondly, medical online support groups have become an important healthcare resource. These groups now provide emotional support, guidance, health information, and medical referrals for nearly all medical conditions—around the world, 24 hours a day and seven days a week, for free. They support self education and self responsibility, encourage patients' initiative and assertiveness, and provide members with an opportunity to help others.\(^\text{1-3}\)

Some e-patient groups, for example, the Life Raft Group (www.liferaftragroup.org), a support group for gastrointestinal stromal tumours, conduct patient initiated clinical research. The group's science team includes a virologist, a microbiologist, a doctor or surgeon, a physicist, an oncologist, and a human genome researcher—all patients or family care givers.

Other groups have established tissue banks or developed patient registries.\(^\text{4}\) For the sickest patients and for those with rare diseases, online support groups can sometimes be more important resources than physicians for many aspects of medical care.\(^\text{5}\) For patients without access to competent professional care, these groups can be the only source of reliable medical guidance. As Eysenbach et al note elsewhere in this issue, it may not be possible to appraise the value of these patient initiated, patient developed resources via the techniques typically used to evaluate professional interventions\(^\text{6}\) (p 1166). We need to develop new tools and methods that can help patients and professionals work together to better understand their dynamics and their potentials.

Thirdly, the net friendliness of clinicians and provider organisations—as rated by the e-patients they serve—is becoming an important new aspect of health-care quality. Net friendly clinicians support their e-patients' new abilities, encourage them to share the results of their online research, and communicate with them by email.\(^\text{7}\) When clinicians respond negatively to e-patients' requests to discuss materials they have found online and act as if they feel that their authority is being challenged by such requests, it may damage or disrupt the doctor patient relationship.\(^\text{8}\)

Fourthly, health researchers should realise that we are witnessing the most important technocultural medical revolution of the past century. We must move beyond critiquing the content of websites, developing proprietary systems, and evaluating the effectiveness of professional interventions. A number of insightful studies of the emerging culture of e-patients have been published, mostly in the social science literature. But they are rarely cited in mainstream medical journals, and their conclusions are unknown to most clinicians.

Much of the fundamental research in this emerging field remains to be done—for example, a census of online support groups, studies of the patient centred email networks that arise when a loved one is ill, and evaluations of the benefits that online patient helpers can provide.\(^\text{9}\) We need more pilot studies; in which patients are taught to provide their own medical care with the best support information technology can provide,\(^\text{9}\) pilots in which professionals and patients explore new ways to work together to care for other patients, and pilots in which teams of professionals and patients look for, evaluate, develop, or apply other new models of e-patient innovation.

Finally, we suspect that the emerging world of the e-patient cannot be fully understood and appreciated in the context of pre-internet medical constructs.

The medical world view of the 20th century did not recognise the legitimacy of lay medical competence and autonomy. Its metrics, research methods, and cultural vocabulary are poorly suited to studying this emerging field. Something akin to a major system upgrade in our thinking is needed, a new cultural operating system for health care in which e-patients can be recognised as a valuable new type of renewable resource—managing much of their own care, providing care for others, helping professionals improve the quality of their services, and participating in collaborations between patients and professionals. Given the recognition and support they deserve these new medical colleagues may help us find sustainable solutions to the seemingly intractable problems that now plague all modern systems.\(^\text{10}\)

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Funding: Part funded by Robert Wood Johnson Foundation grant #E3806.

Competing interests: None declared.

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