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## Perspective

# Patient informaticians: Turning patient voice into patient action

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## ABSTRACT

Historically, patients have held a passive role within healthcare, seeking consultation from and following the directions of providers and their care teams. However, changes in culture, education, and technology are making it possible for patients to proactively develop and implement technologies and approaches for health management and quality of life enhancement—to act as patient informaticians. This perspective reviews the societal shifts facilitating the evolution of patient informaticians as discrete actors within healthcare, describes the work of patient informaticians and how this work differs from that of other patient roles (eg, patient advocates), considers examples of patient informaticians in action, and defines patient informaticians' position relative to the healthcare system.

**Key words:** patients, research personnel, consumer health informatics, patient advocacy, citizen science

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## INTRODUCTION

Informatics has been defined as the science of information, where information is defined as data with meaning.<sup>1</sup> Correspondingly, informaticians study data plus meaning and its usage and effects. Within biomedical informatics, principle actors have included healthcare providers (eg, physicians, nurses, speech therapists), computer scientists and technologists, user interface designers, organizational management professionals, and others. Patients historically have benefited from an informatics approach, but have rarely taken an active role in informatics activities, though consumer health informatics as a distinct field has been in development for at least 20 years.<sup>2</sup> Changes in the social, technology, and healthcare environments, however, have created an opportunity for patients to actively participate in creating and using data with meaning. Patient informaticians have begun taking their place in the field.

Expansion of the patient role over the past decade has facilitated the emergence of patient informaticians as a branch of medical informatics. The adoption of shared decision making as a clinical strategy and the emergence of the participatory medicine movement set the stage for patient-designed, patient-implemented informatics

initiatives. Heightened awareness of informatics development, testing, and continuous improvement processes through dissemination in open access journals has made it possible for hyperengaged patients to design and implement tools to meet their health goals.

Multiple factors have driven, and now support, the emergence of patient informaticians. Rising medical costs present an imperative for patients, who may pay higher premiums and deductibles, as well as a greater share of covered services, particularly when forced to seek care outside limited provider networks. Continuous changes in health plan design and availability make it more difficult for some patients to purchase insurance coverage on insurance exchanges or through brokers, while those covered under government programs may be disqualified due to minimal changes in income or personal circumstances. Uncertainty about future availability of insurance, access to needed members of the care team, and affordability prompt some patients to seek less tenuous routes to health improvement than through the predominant healthcare system.

Beyond financial and insurance-related concerns, a greater societal emphasis on taking responsibility for one's health and being an engaged patient is driving patients to reconsider their relationship

with the healthcare system. Patients have long heard that they need to change their diet, become more active, take their medication as directed, and proactively embrace other healthful practices, but adherence rates remain suboptimal. The marriage of consumer and pervasive health informatics and the increase in high school students taking mathematics and science courses since 1990<sup>3</sup> makes it possible for patients to create solutions to the challenges that previously prevented them from achieving desired health outcomes.

Change within the healthcare system, including a growing willingness by providers to recognize patients as researchers and partner with them to achieve mutual goals, has resulted in greater acceptance of patient-initiated and patient-developed endeavors.<sup>4</sup> Support for patient access to and control of health data by and about patients is growing within the healthcare system,<sup>5,6</sup> and healthcare researchers increasingly recognize the value of engaging patients as co-researchers and identify meaningful, efficacious ways to do so.<sup>7-9</sup> Patient researchers not only can be trained as researchers, but also can function effectively as members of the research team.<sup>10-12</sup> Patients ability to function as researchers is unsurprising, given that patients have already demonstrated the ability to troubleshoot and solve their own care-related problems.<sup>13,14</sup> An international panel of patient advocates influences health information technology policy and development through work with the Health Technology Assessment International's Patient and Citizen Involvement Interest Group.<sup>15</sup>

Too, the growing prevalence of devices and sensors that allow people to track physiological functions, activity, sleep, and other health-related metrics facilitate a more nuanced understanding of personal health and performance. Patients use personal data to find patterns in their symptoms, gain confidence, and improve communication about their health with members of their care team.<sup>16</sup> Although the accuracy of data captured by wearable devices has proven variable, using data from wearables in conjunction with medical measurements has proven successful in identifying Lyme disease and inflammatory responses.<sup>17</sup> Patients have expressed confidence in their ability to use their data to test potential solutions to personal health problems using mobile technology, and a self-experimentation framework lays out a path for teaching patients how to do so.<sup>18</sup>

Through 2016, US\$5.4 billion was invested in digital health start-ups worldwide.<sup>19</sup> Under the Software Pre-Certification Pilot Program, the US Food & Drug Administration (FDA) will evaluate both the software developer and the product as FDA develops tool evaluation criteria,<sup>20</sup> which may support research and development by patient informaticians. FDA now supports manufacturers' sharing of patient-specific information—"information unique to an individual patient or unique to that patient's treatment or diagnosis that has been recorded, stored, processed, retrieved, and/or derived from a legally marketed medical device"—with patients at their request.<sup>21</sup> Though manufacturers aren't required to share patient data with patients, manufacturers can no longer argue that regulatory concerns prevent them from sharing data, which has been a barrier for patients seeking personal data for digital tool research and development. Global type 1 diabetes research funder JDRF has since announced an initiative for development of open protocols for artificial pancreas technology,<sup>22-25</sup> an approach co-developed by the parent of a patient that patients have used to more easily access personal data and/or control automated insulin delivery.<sup>26</sup> And most importantly, patients themselves want access to the data generated by devices they use to better engage with their care team and manage their health.<sup>27</sup>

## PATIENT INFORMATICIANS DEFINED

Work that patients do to improve and/or maintain their health has been recognized as a form of background work—work in which workers are visible but their effort exists within a “background of expectation.”<sup>28</sup> These endeavors, sometimes dubbed “patient work,”<sup>29</sup> take many forms, such as collecting medical records and test results from multiple providers, following up on referral documents, and teaching residents care practices. Consumer health informatics researchers have acknowledged the need for and value of a patient work approach.<sup>30</sup> In their self-directed efforts to restore, maintain, and/or improve their health through interaction with the healthcare system, patient informaticians extend the function of patient work.

Though the work of patient informaticians differs from that of engaged patients, it builds upon fundamental patient practices and skill sets. Patient informaticians identify unmet health needs, parse problems into components that can be addressed through data collection and analysis, devise strategies to overcome barriers, collect and analyze data, interpret results, and implement life and/or care changes to address their identified needs. They define workflows that address health issues of concern to patients that result in improved quality of life and greater satisfaction with the healthcare system. These workflows may be temporary or permanent, and may arise reactively in response to unmet needs or through proactive efforts to achieve patient-defined goals.

Patient informaticians' work differs from other patient work in that patient informaticians act not only at directives of the healthcare system but also on imperatives defined by their and other patients' lived experience. Although much of patient informaticians' work occurs in an established environment (eg, an office), much of what they do is unanchored work,<sup>31</sup> taking place in other locations determined by the nature of the tasks. Patient informaticians may analyze patient work, potentially extending the knowledge base used by traditionally trained researchers and care teams, or may define new forms of patient work during the course of personal initiatives.

The activity of patients in today's healthcare system builds upon the activities of patients who were engaged before them, and the patients of today both benefit and incur harm from previous events. Reflexivity, the observation and consideration of one's actions,<sup>32</sup> is one lens through which patient engagement with the healthcare system has been studied.<sup>33</sup> From this perspective, patients position themselves when writing about their health and health care experiences, and their goals may vary, perhaps substantially, from the goals of those operating the Web sites to which they contribute. Patient informaticians do reflect upon their activity and assume specific positions relative to the healthcare system and other patients. However, they react not to opportunities offered by others within some overt or covert framework created by others, but rather, respond to needs lived by themselves or others they care about without regard for or reference to others' agendas. Furthermore, patient informaticians do not compare their experiences with those of others, as do patients sharing personal experiences via the Web and social media, but instead define and initiate their own experiences within the context of their own goals.

Patient informatics may appear to have much in common with participatory medicine, which has been defined as a movement in which patients and health professionals actively collaborate and encourage one another as full partners in care.<sup>34</sup> Patients participate in managing (or choosing not to manage) their health, though not all patients are “all in” to the same degree. In practice, many others (eg, payors, health policy makers) work with patients and health

professionals as co-managers of health.<sup>35</sup> Although patient informaticians may work with their care team to implement self-developed health management practices and strategies, players such as health policy makers are unlikely to actively participate in patient informatics.

Patients engage with the healthcare system in many ways, and there may be some overlap in the activities of other groups and those of patient informaticians. However, there are also important differences that support differentiation of patient informaticians from others:

- Patient informaticians differ from clinical informaticians in that patient informaticians collect medical, health-related, environmental, and other data to address health and quality of life issues. Clinical informaticians work across the healthcare delivery system “to improve outcomes, lower costs, increase safety and promote the use of high-quality services.”<sup>36</sup> Patient informaticians act across a broad spectrum of landscapes (eg, home, community, schools, worksites) to achieve outcome-focused goals.
- Patient informaticians differ from citizen scientists in that patient informaticians collect data focused on specific health and quality of life issues. Citizen scientists collect large quantities of data to address a broad range of health, science, technology, and other issues,<sup>37</sup> typically under the supervision of career scientists and potentially with the goal of effecting change at the global level. Such data gathering frequently occurs over a long period of time (eg, decades) and involves members of the public who do not know each other and have no connection to each other beyond project data collection.<sup>38,39</sup> In contrast, patient informaticians work within an established community linked by a shared health condition and may aim to develop an individualized solution to a personal health concern rather than a scalable solution to a medical problem.
- Patient informaticians differ from e-patients in that patient informaticians may collect and share data electronically, within or outside the established medical system, to find answers to broad health and quality of life concerns. E-patients work directly with members of their care team to address medical and/or health issues using digital tools.<sup>40</sup>
- Patient informaticians differ from patient advocates in that patient informaticians primarily use technology to address real-life issues in real time. Patient advocates perform a broad range of tasks that directly or indirectly support patients or reduce barriers patients face, such as raising awareness, lobbying legislative bodies, raising and allocating funds, influencing research design, pressuring payors to reimburse costs of medical care, promoting clinical trials and recruiting participants, disseminating research findings, developing online support communities, and others.<sup>41</sup>
- Patient informaticians differ from self-trackers in that patient informaticians structure data collection, analysis, and future work to answer specific questions. Self-trackers gather personal data within defined domains (eg, exercise, sleep) with the goal of learning more about how their body works, rather than creating scalable solutions to specific health problems.<sup>42</sup>

## PATIENT INFORMATICIANS AT WORK

Patient informaticians use self-collected data to address real-world concerns. The union of personal health experience, critical thinking, and subject matter expertise inform medical device development and lifestyle management for improved health and quality of life. The following examples illustrate the problem-solving approaches patient informaticians may take.

The Nightscout Project<sup>43</sup> was launched by a parent who wanted to access data flowing through the continuous glucose monitoring (CGM) system used by his 4-year-old child.<sup>44,45</sup> The ability to continuously monitor a child’s blood glucose level without disturbing the child’s sleep provides improved quality of life, better glucose level control, and the opportunity to live a more typical life, for example by attending sleepovers at friends’ homes. The ability to download blood glucose data to personal devices such as smartphones has been recognized as a potential factor in better glycemic control.<sup>46</sup> In the Nightscout case, the parent hacked into the CGM system and wrote code that provided access to the CGM data via mobile, wearable, and web-based interfaces. This approach allowed the parent to monitor the child at school, during activities, and while asleep without unduly burdening either parent or child. Others who have type 1 diabetes were interested in using this technology, so the parent created the Nightscout Project Web site, publishing the code in an open source format. As word spread about the work via social media, others around the world who have type 1 diabetes began using the information to create devices for their use, sometimes hosting “build parties.”<sup>47</sup>

The development of a system to detect the filling of ostomy bags provides another example of patient-driven informatics. Even when placed and managed with care, ostomy bags can leak, causing embarrassment and inconvenience and, potentially, health issues. Using a cell phone battery and a flex sensor from a video game, a patient developed the 11Health sensor to alert him when his ostomy bag was full and required changing.<sup>48</sup> The patient then navigated the United States and United Kingdom regulatory systems to commercialize the device so that it could be made available to others.<sup>49</sup>

Though technology and software development skills were necessary to create the Nightscout system and 11Health ostomy bag sensor, patient informaticians need not possess technology development skills to undertake patient informatics work. For example, a patient informatician who has Raynaud’s syndrome might wish to better understand the conditions that trigger episodes of cold and numbness in her extremities so that she could regularly exercise outside. To do this, she could collect precise measurements using a home weather station that transmits temperature, humidity, wind velocity and direction, and precipitation readings to her personal computer during the times she wishes to exercise. She could record the clothing worn during each session, perceived extremity sensation and comfort levels, rate of perceived exertion, walking/running time and distance, and other variables of interest. She could then graph weather variables known to trigger episodes against performance and sensation variables to determine the most effective clothing in each set of conditions encountered during exercise, which would allow her to select appropriate clothing to prevent or mitigate the severity of Raynaud’s episodes. She also could work with others who experience similar challenges (eg, those who have systemic lupus erythematosus, peripheral neuropathy) to implement neighborhood-specific guidelines, perhaps meeting with others in a group sponsored by a local healthcare facility. In this way, personal efforts to solve personal health problems can evolve into initiatives that support population health study and management, perhaps in conjunction with health care institutions.

## MORE THAN ENGAGED PATIENTS

Patient engagement has been the subject of increasing interest and study during the past 2 decades. Although the term is loosely defined, it has come to represent a broad spectrum of activities ranging

from consultation to partnership and shared leadership.<sup>50</sup> At all levels of involvement, patients may be active participants in or passive recipients of interventions. In some instances patient feedback, rather than patient action, foments change undertaken by the health system or individual institutions within the system. In effect, these entities may use patients' involvement in support of their own goals, rather than goals defined by patients. Though engagement is an underlying driver of patient informaticians, it is not their primary focus.

The concept of patient-centeredness in health care is similarly amorphous. An integrative model of patient-centeredness based on analysis of 417 journal articles identified 15 dimensions of patient-centeredness.<sup>51</sup> Of these, experts identified "patient as a unique person," "patient involvement in care," "patient information," "clinician-patient communication," and "patient empowerment" as the most important dimensions.<sup>52</sup> Notably, none of these dimensions acknowledges the patient as an active, self-determinant being; rather, all frame patient-centeredness in reference to the healthcare system, an institution, or a provider. Given this fundamental difference in worldview, it is not surprising that patient-centered outcomes research (PCOR) too may be at odds with the approach taken by patient informaticians. PCOR researchers employ a variety of research techniques (eg, focus groups, patient advisory councils, surveys) that may have little, if anything, to do with patient-defined interaction with the health system or informatics. Though such work may inform and/or complement patient informaticians' efforts, PCOR too fails to place the patient at the center of the action.

Despite this key difference, some might argue that the Patient-Centered Outcomes Research Institute (PCORI) and other entities engaged in similar efforts address many of the goals and priorities of patient informaticians, and that as a result the work undertaken by patient informaticians is already being done by PCORI. However, significant differences in purpose, activities, and outputs exist between PCORI and patient informaticians. The most critical difference is structural: PCORI seeks to support patient as partners in research, but awards research funding to health professionals in academic and other health system organizations who define the nature of the work to be undertaken and how patients will engage with the funding recipients. Although patients must be involved in PCORI-funded research, they don't set the research agenda, decide what role(s) patients will play in the work, evaluate the results, identify next steps, make key decisions, or in other ways act autonomously. This incongruity extends beyond research methods; when health services researchers speak of data sharing, they reference data sharing among health researchers, rather than data sharing between researchers and patients<sup>53</sup> despite patients' desire to control the data.<sup>54,55</sup> In contrast, patient informaticians set the research agenda, select or develop methods, conduct the work, analyze the resulting data, and determine how to proceed based on what has been learned.

As with other informaticians, funding is a key consideration for patient informaticians. Although they may lack dedicated laboratory and clinical facilities, through collaboration with clinicians and researchers their work may be supported by traditional funders such as the National Institutes of Health,<sup>22</sup> universities,<sup>44</sup> or private foundations.<sup>26</sup> Crowdfunding has proven successful as a strategy for covering treatment expenses,<sup>56</sup> and it is rapidly maturing as a source of medical research funding via sites such as Medstarr and Consono.<sup>57,58</sup> Patient informaticians also may have greater freedom and flexibility than researchers in academia to access nontraditional

funding arrangements such as venture capital and business incubators. Ultimately, patient informaticians gain funders' support on the strength of their innovation, patient expertise, and determination to succeed.

Given this fundamental paradigm shift, one might wonder about the position of patient informaticians relative to the broader healthcare system. Patient informaticians act in response to the failure of healthcare institutions to meaningfully grasp and address their health-related needs. Although researchers seek to address patients' medical and health concerns, a gap often exists between researcher and patient priorities.<sup>7</sup> Bioethics frames patients as weak and in need of protection,<sup>59</sup> which may limit harm to the most vulnerable patients but also prevents benefit to those who are less fragile or more capable of advocating for themselves. FDA's willingness to meet with patients to discuss how patient-developed technologies can be implemented at scope suggests that there may be a pathway for patient informaticians to function in ways traditionally acted by device manufacturers, software developers, and others with specific, defined technical backgrounds.

Relative to healthcare providers, who typically spend many years in highly proscribed training before treating patients, patient informaticians may have little formal training. Healthcare system stakeholders may argue that this lack of directed education disqualifies patients from practicing informatics. Some may even argue that, lacking this formal background, patient informaticians cannot be regarded as professionals and/or as professional colleagues. However, it is unlikely that providers will refuse to engage with patients who develop tools and methods that support more desirable outcomes, improved health, and/or a more productive patient-provider relationship. Patients' contribution to recognizing, framing, and partnering in their care—and even taking the lead—is no longer in question. The growing acceptance of this reality is facilitating patients' entrée into areas of medicine currently the domain of those with formal background. Successful development and deployment of patient-developed products, such as the 11Health ostomy bag sensor, is compelling evidence for the value of patient informaticians. The work undertaken by patient informaticians will contribute to the emerging learning healthcare system, and thereby ensure a role for patient informaticians in 21st century medicine.

## CONCLUSION

Although patient informaticians have yet to achieve the recognition experienced by informaticians in other branches of informatics, patient informaticians now act as distinct players within healthcare. Their efforts establish patients as active, self-determinant beings attaining functionality not facilitated by current standard-of-care approaches. Whether patient informaticians work formally within the healthcare system or informally in patient communities, their goal is the same: to improve health outcomes and quality of life by using knowledge and technology in novel ways. In pioneering new strategies and tools, patient informaticians convert failure via healthcare system-defined paths to success via self-defined and self-developed approaches.

## CONTRIBUTORS

C.P. conceived the ideas and wrote the manuscript.

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