VIEWPOINT

Engagement, Peer Production, and the Learning Healthcare System

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Physicians deliver about half of indicated care, and patients do about half of what it takes to stay healthy, despite the best intentions and tireless efforts of both physicians and patients. The learning healthcare system (LHS) has been proposed as a solution. As envisioned by the Institute of Medicine, an LHS would "generate and apply the best evidence for the collaborative healthcare choices of each patient and provider, drive the process of discovery as a natural outgrowth of patient care, and ensure innovation, quality, safety, and value in healthcare."[1(p354)] But this model begs the question: Who is learning? And how? Traditional models suppose that highly trained experts—expert clinicians and expert researchers—are best suited for producing information, knowledge, and know-how. This reliance, however, on a small group of experts to improve health care and health outcomes has yielded the current system performance and impedes immediate, continuous, and transformative improvement. A new model of production is necessary.

Commons-Based Peer Production and the LHS

Commons-based peer production describes a model of production in which the creative energies of many people are coordinated into large, meaningful projects.[2] This contrasts with firm production, in which production is centrally coordinated, and market-based production, in which production is driven by supply and demand. Wikipedia, the best-known example of peer production, stands in contrast to the firm-produced (and defunct) Microsoft Encarta. The Human Genome project, an example of scientific peer production, shared data in advance of publication and produced results years ahead of schedule.

Applying the concept of peer production to the LHS suggests distributing the means of producing information (eg, clinical data and patient-reported outcomes), knowledge (informal insights and formal research), and know-how (expertise) as broadly as possible to patients, family members, clinicians, and researchers. Successful commons-based peer-production models make objectives modular, tasks granular, and integration effortless.[3] Wikipedia, for example, allows individuals to work on one entry (modular), makes it easy to sign in and edit an entry (granular), and has a platform—the Wiki—that aggregates individual contributions (effortless integration).

An example of an emerging peer-production LHS is ImproveCareNow (ICN), a network of pediatric gastroenterology practices whose mission is to transform the health of, the care of, and the costs for children and adolescents with Crohn disease and ulcerative colitis (ie, inflammatory bowel disease). The ICN network has partnered with the Collaborative Chronic Care Network (C3N) Project, supported via a National Institutes of Health Transformative Research grant (R01 DK085719), to develop and test interventions to become a peer-production LHS.[4] As a network that engages patients, families, and clinicians in research and improving outcomes, ICN has achieved remarkable success. Since 2007, the proportion of patients in remission (with inactive disease) has increased from 55% to 77%.[5] The ICN network has grown to 58 sites that provide care for 17 000 patients in 30 states; about one-third of all children with inflammatory bowel disease in the United States.

Engagement and the Peer-Produced LHS

In a peer-produced LHS, engagement is the extent to which an individual takes part in the production of information, knowledge, and know-how. Engagement applies to clinicians and researchers, as well as to patients and their families. As noted by Carman et al,[6] engagement occurs at the policy level (How do we improve the health care system?), at the health care organization level (How do we improve the health of a population of patients?), and at the personal level (How do we improve my/my child's/my patient's health?). Defining engagement in the context of a peer-produced LHS supplements existing definitions, such as "actions that individuals must take to make the most out of available healthcare"[7(p7)] and that frame it in terms of the relationship between patients and health care providers as they work together to "promote and support active patient and public involvement in health and healthcare and to strengthen their influence on healthcare decisions, at both the individual and collective levels."[8(p10)]

We posit that engagement exists along a continuum: from awareness, to participation, to contribution, to ownership of the peer-production system. Awareness results when individuals know about the system (eg, there is a network called "ImproveCareNow," and patients, doctors, and researchers can be part of it). Participants use existing tools but are likely to consume more information, knowledge, or know-how than they produce (eg, participating in an inflammatory bowel disease education day or research study, or reading an ICN blog post [http://www.improvecarenowblog.org]). As more tools are available and easier to use, options for participation expand. Contributors actively use and improve existing resources to produce new information, knowledge, or know-how (eg, working on a research team to develop and test a tool or joining a Care Center Quality Improvement team). Owners lead new initiatives and create new resources (eg, developing a parent mentoring program or developing Care Center Wel-

come Kits for hospitalized children). As with any network phenomenon, not everyone chooses to engage to the same degree.[9] A relatively small group of owners or "lead users"[10] are likely to make outsize contributions, while the majority of stakeholders participate by using the existing tools.

Expanding Engagement and Enhancing the Peer-Production LHS

Expanding engagement in an LHS requires the existence of a system with ready avenues for and receptivity to engagement among all stakeholders. In addition to transforming norms and culture around traditional roles of patients and clinicians, the C3N Project has developed tools that make it easier for more people to participate in the production system. Clinician participation is made easier by informatics that populate the patient registry as a by-product of clinical charting, as well as automated reports for pre-visit planning and population management. Patient participation is made easier by tools that facilitate health status tracking, understanding laboratory results, highlighting key issues for discussion in advance of the clinical encounter, and collaborating with clinicians to understand symptom variation and to choose best treatments. A federated institutional review board, an intellectual property commons framework, stage-gate innovation management, and data sharing and authorship policies facilitate researcher participation.

Strategies to purposefully foster engagement are essential to developing a critical mass for a self-sustaining LHS. We have launched a campaign to increase awareness and participation in the ICN network among patient and family stakeholders (http://healthiertogether.org/) and are encouraging participation by continuing to make tools easier to use and by facilitating networked communication. We are identifying and developing contributors by supporting ICN Care Centers to include parents on their Quality Improvement teams and by developing a learning community with these parents. We are also developing ways to support owners by partnering with them to use ICN as a "distribution channel" to multiply their efforts.

Conceptualizing engagement in the context of the peer-produced LHS suggests a strategy that could accelerate realization of the Institute of Medicine's vision of an LHS, that could increase capacity by transforming norms for involvement and making participation easier, and that could, at the same time, increase capability by increasing the number of knowledgeable contributors and owners—these are the people who will contribute to improving existing tools, to governance, and to creating new tools, which would, in turn, raise awareness, multiply avenues for participation, and create more participants, contributors, and owners. Such a generative cycle can harness the inherent motivation and collective intelligence of all stakeholders to improve health, care, and costs on a potentially massive scale.

ARTICLE INFORMATION

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