


EXPERIENCE REPORT

Organizing for collaboration: An actor-oriented architecture in ImproveCareNow

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Abstract

Background: Collaborative learning health systems (CLHSs) enable patients, clinicians, researchers, and others to collaborate at scale to improve outcomes and generate new knowledge. An organizational framework to facilitate this collaboration is the actor-oriented architecture, composed of (a) actors (people, organizations, and databases) with the values and abilities to self-organize; (b) a commons where they create and share resources; and (c) structures, protocols, and processes that facilitate multi-actor collaboration. CLHSs may implement a variety of changes to strengthen the actor-oriented architecture and enable more actors to create and share resources.

Objective: To describe and measure implementation of elements of the actor-oriented architecture in an existing Collaborative Learning Health System.

Methods: We used the case of ImproveCareNow, a CLHS improving outcomes in pediatric inflammatory bowel disease, founded in 2006. We traced several network-level indicators of actor-oriented architecture between 2010 and 2016.

Results: We identified measures of actors, the commons, and ways that have made it easier for network member sites to participate. These indicators show ImproveCareNow has made changes in the three elements of the actor-oriented architecture over time.

Conclusion: It is possible to measure the implementation of an actor-oriented architecture in a CLHS. The elements of the actor-oriented architecture may provide a conceptual framework for their development and optimization. Metrics such as those described here may be actionable indicators of the "health of the system."

KEYWORDS

chronic care, collaborative learning health systems, organizational theory

1 | INTRODUCTION

Activities aimed at developing learning health systems (LHSs) are gaining momentum and are increasingly widespread.¹ The way people are organized in an LHS matters in the control and coordination of

resources and activities² and ultimately influences system growth, effectiveness, and longer-term success. Understanding and advancing LHSs thus requires an understanding of how they are organized.

We have recently described network-based collaborative learning health systems³ (CLHSs), which have been shown to improve

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outcomes across a variety of conditions.⁴⁻⁷ These organizations use an actor-oriented architecture (AOA).² The AOA consists of actors (people and institutions) with the values and capabilities to self-organize; a commons where they create and share resources; and structures, protocols, and processes that make it easy to form highly functional teams. This organizational structure differs from hierarchical or matrix organizations in that it is more flexible and adaptable, allowing distributed decision-making to enable large groups of people (eg, patients, families, clinicians, researchers, and health system leaders) to self-organize to solve health care system problems important to them.²

Increasing the number of actors with the values and capabilities to self-organize entails both increasing awareness of the learning health system and one's role in it and making it easier for people to participate in and improve it. CLHS leaders build a sense of shared responsibility and commitment to the shared goal of improving outcomes.³ Collaboration is an important cultural norm, aimed at creating an environment of "all teach, all learn." This captures an important part of CLHS culture: If someone has a good idea for improving outcomes, he or she would eagerly share so that others (and therefore the whole network) can benefit. Similarly, if someone becomes aware of a better tool or process, he or she is expected to "steal" and adapt it—to use it to improve outcomes at his or her home institution. As people become more involved, they may be more likely to self-organize and to use and improve tools to speed the production and sharing of information, knowledge, and know-how.⁸

A commons is a shared platform for creating and sharing resources. CLHSs use data registries and online sharing platforms to create and share tools, data, know-how, standards, and shared situational awareness. Networks and teams receive monthly reports on network functioning and key process and outcome measures and can compare their system's performance to their peers.³

Policies around intellectual property and privacy that promote innovation and sharing, as well as the technology that facilitates collection and sharing of information, knowledge, and know-how,⁹ are some of the protocols, processes, and structures that facilitate multi-actor collaboration. Others include, for example, using standardized agreements for sharing data, or using a common learning system in which actors can easily connect with and understand others and use common data and methods to solve shared problems.

Beginning in 2010, ImproveCareNow began implementing a variety of network-level interventions to make it easier for more people and care centers to collaborate. We describe these interventions and trace measures indicating their implementation.

2 | RESEARCH INTEREST

How might we understand and measure organizational changes that could facilitate collaboration? In this study, we describe, and trace over time, a set of metrics corresponding to interventions made by ImproveCareNow (ICN), a mature CLHS focused on pediatric inflammatory bowel disease (IBD: Crohn disease and ulcerative colitis) as it

implemented organizational changes consistent with the actor-oriented architecture.

3 | METHOD

3.1 | Human subjects

This research was determined to be exempt from IRB review as research involving the study of existing data, where the information is recorded in such a manner that subjects cannot be identified, directly or through identifiers linked to the subjects.

3.2 | Setting

ImproveCareNow (ImproveCareNow.org) has created a collaborative community where clinicians, researchers, parents, and patients learn together and continuously improve to bring about more reliable, proactive IBD care for children and youth. Its purpose is to transform the health, care, and costs for all children and adolescents with IBD by building a sustainable collaborative chronic care network. As of March 2019, there were 109 care centers in ImproveCareNow, with 950 pediatric gastroenterologists and 30 000 current pediatric patients with IBD, of which 82% were in remission. These care centers are generally pediatric gastroenterology clinics within academic or community medical centers or freestanding pediatric gastroenterology practices. Care centers pay an annual membership fee to join ImproveCareNow; physician, nurse, QI coordinator, and other team member time are also contributed. Parents/other caregivers and patients are active at every level of the ImproveCareNow organization (for example, five of the eight members of the Board of Directors are parents or patients) and are increasingly partners in quality improvement activities at their care centers.

Data are collected at each clinic visit by CITI-trained clinic staff, who explain the purpose and risks of data collection for research purposes. Data are used for clinical care and population management for all pediatric IBD patients seen at each ImproveCareNow care center. Data are used for research purposes if parents (or the patient if 18 years or older) provide informed consent (71% of patients have consented to have their data used for research purposes).

ICN care centers undertake a structured onboarding process in which they complete required, standardized IRB and business and legal agreements. Centers must also participate in a thorough program of quality improvement (QI) instruction called "QI Fundamentals" that addresses use of the registry and the reports that are generated from it to guide QI efforts. These activities, which are completed over a 6-month period and culminate in attendance at a teams' first Community Conference include educational modules, executing a small QI project, orientation to the ImproveCareNow culture and collaboration processes, and training around using data for improvement. No data are available on the immediate impact of this training on patient care or clinical schedules as data collection regarding team processes and

outcomes generally begins once the QI Fundamentals Course is completed. ICN uses a dashboard of routinely tracked measures to monitor and improve a range of outcome, process measures, data quality/completeness, research, and participation measures, which in aggregate illuminate the functioning of the CLHS.

3.3 | Changes made by ImproveCareNow

Launched in 2013, the ICN Exchange¹⁰ is an online knowledge management and exchange platform where people can post, share, download, and adapt documents, videos, and other artifacts to share tacit knowledge for improvement. The ICN Exchange, maintained by Cincinnati Children's Hospital Medical Center's Biomedical Informatics, is used by the ImproveCareNow community for sharing tools, insights, and ideas. For example, a nurse who devises a reliable process for ensuring that labs are drawn before the clinic visit or a patient who has learned how to place his own nasogastric tube for enteral feeding¹¹ can share the documents or videos and anyone with an account can use them. Postings are not formally reviewed, but there are opportunities for the community to comment, save content to their own boards, and like/dislike. A small group of superusers monitors the content for blatantly inappropriate postings. However, the culture of ImproveCareNow is such that people (a) submit their best work and (b) test new interventions iteratively to determine effectiveness in their own setting.

ImproveCareNow's enhanced registry¹² has two main advantages over standard research or improvement registries. First, it allows for "data in once"—using standardized forms, specific data elements necessary for improvement and research are collected in a structured format as a by-product of clinical documentation and sent to the electronic record and, via an automated process, to the registry. This vastly reduces the burden of data extraction and entry and ensures timely availability of the data for a variety of approved uses. Second, by having ready access to up to date clinical data, the registry is used to facilitate clinical care (for example, by creating automatic pre-visit planning reports), quality improvement (for example, by timely reporting of center and network level process and outcome measures), and research (for example, by facilitating preparatory-to-research queries of samples potentially eligible for research studies). Details of the enhanced registry architecture and data models can be found in Marsolo et al.¹² Based on their experience, it is estimated that setting up the process requires approximately 20 hours of effort from an institution's IT department.

ImproveCareNow has twice yearly Community Conferences where center-based teams from across the entire network meet to share knowledge and learn new skills. Community Conferences cover a wide range of topics relevant to the community and include scientific sessions, skill building and educational workshops, role-specific work time, and community building events. When the network began, only clinicians attended, but beginning in 2010, parent and patient partners attend and now have major roles in planning the Community Conferences and teaching.

ImproveCareNow has focused, beginning in 2012, on facilitating collaboration at the level of the organization—all centers were offered standardized regulatory and legal agreements to reduce hurdles to full participation in the network. A federated Institutional Review Board (fIRB) allows care centers' institutions to rely on a central IRB for human subjects research review. Care centers that do not rely on the fIRB use their own IRB. At the care center level, having the option to rely on a fIRB reduces the start-up time when joining ImproveCareNow. At the network level, an fIRB vastly simplifies the process of changing existing or adding new research protocols. Streamlined regulatory processes include ImproveCareNow's standardized Business Associate Agreements (BAAs) and Data Use Agreements (DUAs). As with a fIRB, using these standard legal agreements reduce the barriers and delays often associated with negotiating such agreements when a new care center joins ImproveCareNow.

3.4 | Analysis

We selected indicators of the actor-oriented architecture elements that were face-valid, already collected data, and displayed these measures over time on run charts for the period 2006 to 2016.

4 | RESULTS

We selected six existing network-level metrics that could be used to indicate the three elements of the actor-oriented architecture. We used two indicators to indicate "actors with the values and abilities to self-organize"—the number of accounts on ICN Exchange (an indicator of how many people use the Exchange) and the number of parents and patients attending Community Conferences (an indicator of how many highly involved parents and patients there are). We used two indicators to illustrate "the commons"—the number of pins (uploads) on the ICN Exchange and the number of patients registered and with data in the registry. We used two indicators to illustrate ways to make multiactor collaboration easier—the number of Centers using a federated Institutional Review Board and the number of centers using standard legal agreements.

Figure 1 displays the run-charts, with a standard time scale for the six measures of the actor-oriented architecture. As can be seen, there is a steep increase in these measures, with increasing numbers of accounts on the Exchange (and of regular users [data not shown]) and patients/parents at Community Conferences, pins on the Exchange and patients registered in the Enhanced Registry, and centers using a federated IRB and standard legal agreements.

5 | DISCUSSION

We have described a set of network-level changes implemented by ImproveCareNow and metrics that indicate the presence of an actor-oriented architecture in this collaborative learning health system.

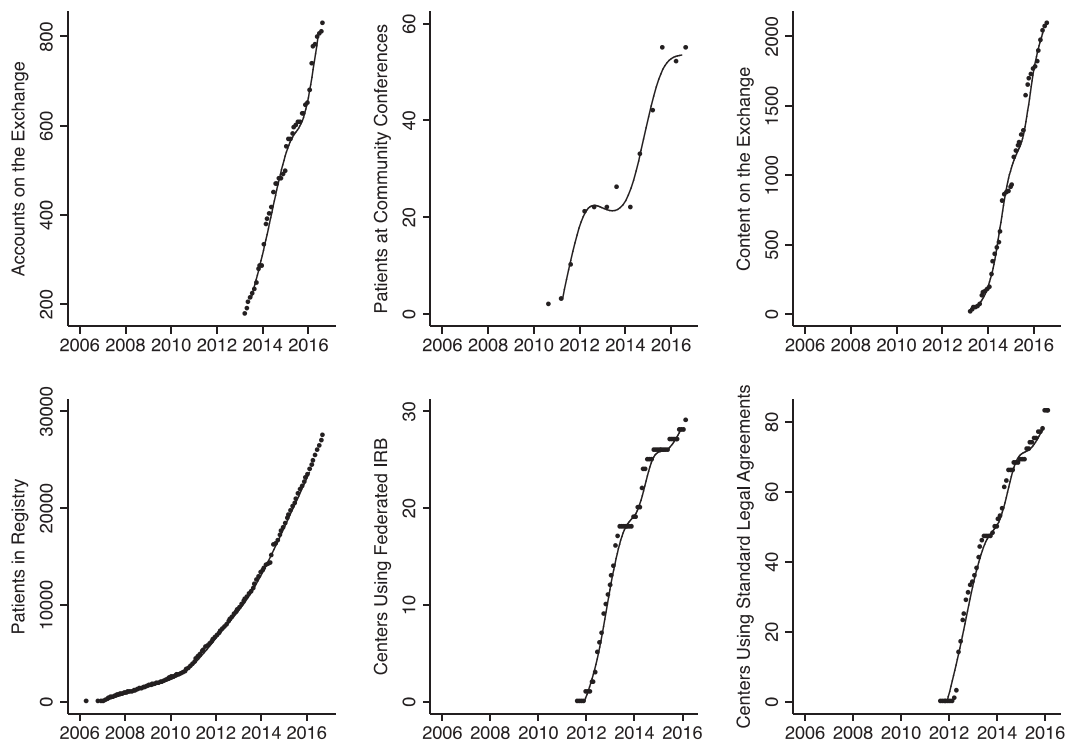


FIGURE 1 Time change in six actor-oriented architecture measures for ImproveCareNow

These metrics show that ImproveCareNow has made organization-level changes that have increased the number of actors in the network and the degree to which the actors are able to create and share resources in a commons and has implemented policies that make it easier for care centers to join this multiactor collaboration. This study is significant because it is the first quantitative description of an actor-oriented organizational scheme in a CLHS.

Fjeldstad et al present four cases from diverse sectors that use the actor-oriented architecture, including consulting, computer operating systems, computer servers, and the military.² Given the breadth of settings in which this organizational scheme can be found, it is not surprising that it can be applied to health care even if it is unusual. Being able to describe and measure elements of the actor-oriented architecture, however, may enable other health care organizations to consider ways to become effective CLHSs. It is also a step towards developing an actionable set of measures—a set of CLHS vital signs—for those seeking to instantiate and optimize CLHSs.

Why might the AOA be a suitable model for a CLHS organizational architecture? As described by Fjeldstad et al,² the advantage of an actor-oriented, compared with a hierarchical organization, is the speed and flexibility by which resources can be coordinated to meet emerging opportunities and threats. Miles and Snow¹³ refer to this as dynamic fit, or how well an organization can adapt to maintain fit with its environment over time. Given the astonishing rate of growth of medical knowledge and the sheer number of phenotypes and treatments available, central determination and enforcement of clinical best practices ensure obsolescence. Rather than specifying a set of

best practices, a CLHS is a platform for learning which practices might be promising in which circumstances. As such, the speed and flexibility in resource allocation and coordination that an AOA enables are extremely important. Moreover, the AOA enables people to interact in new ways, relatively autonomously.

A CLHS, like health care broadly, is a complex system.^{14,15} Because the nature of a complex system is dependent on the interaction among its constituent parts, a good starting point for changing such a system is to think about how to enable the parts of the health care system—say doctors and patients—to interact differently.¹⁶ Wagner's Chronic Care Model^{17,18} suggests that good outcomes result from productive interactions between prepared, proactive clinical teams and informed, activated patients, in other words, interactions between clinicians and patients characterized by co-production of good care.¹⁶ This notion of co-production, at full scale, is a key characteristic of a CLHS and is facilitated by the AOA.

We recognize weaknesses in this study. It is a single case, and the generalizability is unknown. The metrics gathered were based on existing data collection and not designed specifically for this purpose—there are likely other measures to indicate this organizational form. We do not have denominators for these measures. We also do not know the extent to which these organization-level indicators are related to individual-level collaboration. More research is required to better characterize the actor-oriented architecture and examine its impact on collaboration and outcomes. Nevertheless, this study provides a framework for describing an organizational architecture, which serves as a useful conceptual model for a collaborative learning health system.

CONFLICTS OF INTEREST

David M. Hartley, George Dallal, and Sarah Myers declare no conflicts of interest. Michael Seid and Peter A. Margolis declare a financial interest in intellectual property licensed by CCHMC to Hive Networks, a company developing information technology to support collaborative learning health systems.

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