

RESEARCH REPORT

Putting the network to work: Learning networks in rapid response situations

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Abstract

Introduction: The rapid response to COVID-19 has necessitated infrastructural development and reorientation in order to safely meet patient care needs.

Methods: A qualitative case study was constructed within a larger ethnographic field study. Document collection and fieldnotes and recordings from nonparticipant observation of network activities were compiled and chronologically ordered to chart the network's response to changes in epilepsy care resulting from COVID-19 and the rapid transition to telemedicine.

Results: The network's response to COVID-19 was characterized by a predisposition to action, the role of sharing as both a group practice and shared value, and the identification of improvement science as the primary contribution of the group within the larger epilepsy community's response to COVID-19. The findings are interpreted as an example of how group culture can shape action via a transparent and mundane shared infrastructure.

Conclusions: The case of one multi-stakeholder epilepsy Learning Network provides an example of the use of infrastructure that is shaped by the group's culture. These findings contribute to the development of a social theory of infrastructure within Learning Health Systems.

KEYWORDS

COVID-19, infrastructure, learning health system, learning network, telemedicine

1 | INTRODUCTION

In March, 2020 coronavirus disease 2019 (COVID-19) began to affect major population centers in the United States. Immediately, healthcare organizations began to respond with a rapid switch to telemedicine.¹ In their adaptation, healthcare providers faced a number of challenges, including disparities in patients' access to smartphones and computers to participate in telemedicine care, the management of information and knowledge in an uncertain environment, and the management of complex human factors that surrounded the pandemic, such as provider morale, anxiety, and access to personal protective equipment.

While some healthcare systems may have had to create new infrastructures for coordinating their response to COVID-19, others may have been able to use an existing infrastructure to coordinate action.^{2,3} In either case, disasters like pandemics have the ability to lay things bare: "As societies respond to these challenges, features that we have taken for granted suddenly become transparent. For a moment, our own world can become anthropologically strange" (Dingwall et al.,⁴ p. 167).

Infrastructure studies, a prominent subfield within Science and Technology Studies (STS), takes analytic advantage of moments where the taken-for-granted features of everyday life become apparent.⁵

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The idea that infrastructures are invisible under normal circumstances is fundamental to this field.^{6,7} Noticing infrastructures happens most commonly when those infrastructures break down, but, as in the case of the COVID-19 pandemic, infrastructures can also become visible when everything else breaks down around them.

In this article, I present a case of how the members of one Learning Health System reoriented their work to respond to the effects of the COVID-19 pandemic on their network members. In doing so, I argue that this case broadens our understanding of the infrastructural aspects of Learning Health Systems (LHS). One of the central issues in the field of LHS is how to develop the infrastructures that support the work of the LHS.⁸ When issues of infrastructure are raised, what is most often discussed is the information infrastructure that underpins the data-gathering and aggregation that enable the continuous improvement work of the LHS.⁸ But these are not the only properties and actions of infrastructures.

Existing research on Learning Networks, one form of LHS, emphasizes the role of people and community—in addition to other elements of infrastructure—in doing the work of the LHS. Past work has emphasized that Learning Networks have an actor-oriented architecture, which “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” (Seid et al,⁹ p. 2). There is also a shared infrastructure across networks that can be customized to individual networks’ needs.⁹ Thus, there are some standardized elements of infrastructure, but also a recognition that infrastructure needs to be adapted for the particular needs of a given network. Researchers in this field have called for “detailed studies of the mechanisms by which learning networks lead to improved results” (Britto et al,¹⁰ p. 944).

The work presented here addresses that call: I examine the social elements of Learning Network activity, producing theoretically informed explanations of how Learning Networks accomplish their work. Similar to Collier (2011, as described in Larkin¹¹), my interest in infrastructure is not simply in the ways that infrastructures make themselves known in the world. Rather, I turn my focus to “practices of conceptualization that come before the construction of the systems themselves and which are engineered into them [...] Infrastructures become the material evidence of this transfer” (Larkin,¹¹ p. 332). As part of this work, I examine how a group’s culture is made material in and through a group’s infrastructure.

How and why should we study infrastructures? In STS, studying infrastructures is often described as studying the mundane. In fact, Leigh Star⁶ has famously written that infrastructure is “frequently mundane to the point of boredom” (p. 377). This humorous phrasing draws one into a reorientation of topics that are taken to be boring, showing that they contain phenomena of great interest to scholars of infrastructure: how human activity becomes coordinated, how information is shared among group members, and how groups cope with infrastructural breakdown.

Infrastructures have a variety of properties. Relevant for the present case are that infrastructures do not have to be built anew for

each process, and infrastructures generally support ongoing activity in ways that are invisible to the user.⁷ Furthermore, infrastructures are inhabited by members who know how the infrastructure works and how to use it.⁶ Members within infrastructures do ongoing work to connect different infrastructures and to work across them.¹² And, finally, infrastructures become visible when they break down.⁶

While many cases in the literature examine infrastructural breakdowns and effortful cross-infrastructural work, I present a different sort of breakdown: a breakdown of wide-scale normal operations that makes it difficult to carry out the work of the group. Below I describe the specifics of the case and discuss the lessons it can teach us about effortful infrastructural work and the infrastructural aspects of Learning Health Systems.

2 | QUESTIONS OF INTEREST

How did a Learning Network leadership team use the network’s existing infrastructure to support the network community during the COVID-19 response?

What can this case teach us about the infrastructural aspects of Learning Health Systems?

3 | METHODS

3.1 | Case description

The Epilepsy Learning Healthcare System (ELHS) is national multi-stakeholder Learning Network of patients, patient and family partners, providers, researchers, community services providers, and advocates working together to improve healthcare and quality of life for people with epilepsy. Currently, 12 academic medical centers, 6 Epilepsy Foundation local offices, and 10 Partner Organizations are involved in the ELHS. ELHS is a network focused on quality improvement, and has a number of ongoing working groups that are designing and testing new workflows and data collection processes to understand and reduce variation in epilepsy care. These working groups are a major focus of ELHS activity.

ELHS was founded in 2018 as part of a pilot initiative to build Learning Health Systems that was supported by the Patient-Centered Outcomes Research Institute (PCORI) and led by the Anderson Center for Health Systems Excellence at Cincinnati Children’s Hospital Medical Center. Both ELHS and the Anderson Center, as well as three other networks similar to ELHS, are case sites in an ongoing qualitative study I have conducted since June 2018.

In keeping with the tradition of interpretive ethnography, which uses long-term engagement with a group to learn about group culture and practices, this analysis seeks to describe how the culture of a group shapes the group’s course of action.¹³ While culture does not determine thought or action, one effect of culture is that it makes some courses of action seem more logical than others. In this case, I examine how different elements of ELHS’s culture,

namely shared values and practices, shaped their course of action during the COVID-19 response, such that certain courses of action seemed logical.

3.2 | Data collection

For this analysis, I constructed a case study within the ongoing qualitative field study described above in order to examine how ELHS responded to the COVID-19 pandemic. Because ELHS is distributed across so many participating centers, understanding the coordination efforts of the ELHS Leadership Team is crucial for understanding how ELHS responded to COVID-related changes in patient care. Thus, I focus here on the actions of the Leadership Team, which coordinates the different core groups and working groups in the network, in which the network members participate.

The case study begins on March 16, 2020, the day ELHS leadership sent an all-network email acknowledging the pandemic and announcing that much of the normal work of the network, particularly working group meetings, new site recruitment, and provider-level data collection, would be temporarily suspended. The reason for the suspension of normal network activities was because clinical operations at each site were in upheaval as those sites, and the institutions they are embedded in, rapidly reconfigured clinical operations to expand telemedicine services. Another crucial event for this analysis was an ELHS leadership meeting that occurred on March 24, 2020. During this meeting, leaders proposed different ideas for supporting the ELHS network members and patients in the shift to telemedicine and the overall COVID-19 response. The case study's end point is the all-network Spring Learning Session on April 28, 2020. This was the event that quickly came into focus for the leadership team as a major opportunity to share relevant information about the COVID-19 response with all network members.

The data sources I draw on are field notes, recordings and documents describing the events of the network in March and April, including ELHS leadership meetings, monthly all-network calls, the all-network Spring Learning Session, the monthly network newsletters, and network emails. During these events and in these documents, the ELHS leadership team actively articulated and negotiated the role of the network in responding to the COVID-19 pandemic.

3.3 | Data analysis

The data sources identified above were compiled, transcribed where necessary, and chronologically ordered. This arrangement of data had two main impacts: it represented the network's evolving awareness of the impact of COVID-19 on network activities and the broader epilepsy community, and it allowed me to characterize the leadership team's ongoing negotiations about the proper course of action. In the course of the analysis, I summarized the content of each event, identifying ideas put forth by network leaders about how to respond to the crisis, as well as morally inflected articulations of the network's

specific role and purpose in the context of the larger community of epilepsy providers, community services, and patient and family partners, who were all simultaneously developing responses to COVID-19. I also identified infrastructural elements of the network that were repurposed to assist in the circulation of COVID-related information within the network.

3.4 | Human subjects

The protocol for this research study was reviewed by the University of Michigan IRBMED (HUM00148389) and determined to be exempt and not regulated.

4 | RESULTS

The transition to telemedicine involved the rapid creation of new infrastructures in healthcare systems around the world. However, not all infrastructures had to be developed de novo. As I describe, organizations like ELHS were able to repurpose elements of their infrastructure to support network sites in making the transition to telemedicine. The ability to address a novel problem with a pre-existing infrastructure is a hallmark of a learning health system, and to see it in motion, as I show here, is to see how the network infrastructure can be put to work.

Below I discuss three findings. First, I describe how ELHS reoriented their work to focus on supporting members sites as they responded to COVID-related changes to clinical operations. Second, I discuss how leadership team members articulated the specific role of ELHS in the overall COVID-19 response within the broader epilepsy community. The particular way in which ELHS leaders articulated their response allows us to understand important aspects of the ELHS culture: their predisposition to action, the role of sharing as a network practice and group value, and their identification of improvement science methodologies as the logical contribution of a group like ELHS to the overall COVID-19 response. Finally, I identify discrete and mundane elements of the ELHS infrastructure that ELHS leaders used to share information and support network members' transition to telemedicine. While the topic of the paper is the rapid shift to telemedicine in light of COVID-19, the analysis and findings focus on infrastructure as a general property of Learning Networks.

4.1 | Reorienting the network's activity

The ELHS leadership halted most normal network activity during the initial COVID-19 response. This meant that workgroup meetings, site recruitment, and clinical data collection were suspended as network site teams focused on changes in their own clinical operations. The immediate reduction of normal work was accompanied by an expression of support for sites and an acknowledgement that site leaders'

limited ability to participate in network activities like clinical data collection was not a problem.

For those who could continue to participate in network activities, monthly all-network calls took on a crowd-sourcing role. A request for input and sharing was circulated that asked sites to share input on: “How COVID-19 is impacting your practice/team,” “What work for ELHS seems doable from your perspective in the near future,” “Any recommendations/shared best practices or questions on the above items or other,” and “Any successes/barriers you can share from your recent ELHS work in practice.” These questions oriented participating sites toward sharing information with other sites and with the Leadership Team. After this all-network call, the notes and call recording were shared with all network members so that sites could learn from each other’s successes and challenges asynchronously.

In addition, the newsletter, a second information-sharing element of the network infrastructure, was repurposed as a mechanism to share COVID-related information with network members. As one leadership team member brainstormed:

I think that warrants maybe full attention in the upcoming [...] newsletter for April that I send out. I think I [could] disseminate everything that you're doing via [the newsletter] and pull together any resources, and I can reach out to everyone separately to see what they have from all of these sources and just focus our next newsletter on COVID coping for ELHS or epilepsy practice overall.

Two aspects of infrastructures⁶ are that they are transparent, meaning that the infrastructure can be repurposed, and that they are built on an installed base, which brings constraints to the possibilities of infrastructural change. With these two properties in mind, it is possible to observe how the ELHS leadership team reoriented the *content* and *activity* of ELHS, but retained the existing elements of the ELHS infrastructure, namely the monthly all-network call and the newsletter.

4.2 | Articulating the network's role in the COVID-19 response

As changes to network events were put into place, ELHS leadership discussed how best to respond as a network to patient care and patient self-management concerns that were arising within the epilepsy community. Certain considerations emerged as semantic themes¹⁴: the importance of only using network members' limited time for content that was relevant to responding to COVID-19, as well as the role of ELHS in helping patients and providers cope with disparities in access to telemedicine technology. There was also an awareness that one benefit of being in a networked system was that certain functions could be centralized, relieving the burden of individual sites organizing similar processes in parallel. But these discussions also contained latent themes¹⁴ that can be interpreted as revealing

important elements of ELHS's group culture. These themes are (a) sharing is both a value and a practice, (b) learning networks are predisposed to act, and (c) improvement is ELHS's proper contribution during the crisis.

4.2.1 | Sharing is a value and a practice

The notion that network members share their challenges and successes and that the leadership team use the network infrastructure to aggregate and further share this information was a practice and value that characterized ELHS's work. This could be observed in the expectations for sharing that ELHS leadership set for network members who would be attending the March all-network call:

What team successes can you share so we can celebrate? What team barriers are you working to overcome? Another team may be dealing with the same barrier and we learn so much through sharing.

In this instance, sharing is presented as a conventional practice of the group that leads to the network's learning. In addition to being a practice, sharing is also a value that is reinforced during ELHS all-network activities and communications:

We were thrilled to hear so many teams share updates & learnings on the best practices they are implementing at their hospitals and organizations in light of COVID-19. It was an amazing example of our network being Stronger Together.

Star⁶ describes one property of infrastructure as that infrastructure is linked to conventions of practice such that “Infrastructure both shapes and is shaped by the conventions of a community of practice” (p. 381). Star developed this property of infrastructure to describe the limits that material infrastructure can have on the use of a technology, as well as resistance to infrastructural change on the grounds that it would violate conventional group practices. Sharing, in this instance, is both a conventional practice and a value in ELHS and it shaped the infrastructural elements, such as the newsletter and all-network call, that were put to work in the network's response to COVID-19.

4.2.2 | Learning networks are predisposed to act

Another feature of the ELHS COVID-19 response was that network leaders were predisposed to act, and moreover, that they accepted acting as a network to respond to COVID-19 as a matter of course. This predisposition toward action was linked closely to ELHS leadership's sense of their network's purpose. For example:

Because I field probably 30 or 40 questions a day of, “what's the data on this?” You know, “how do we

approach that?" You know, "what's best practice for this?" And *we don't have any of those answers, but I think we can have those answers*, or at least preliminary answers, on a lot of those issues very, very quickly. [...] *We can do that. We need to start doing that.* And then we need to disseminate not just to our members, but in this setting of crisis, *we need to show that this way of working is the way to work.* [Emphasis added]

Here, one network leader forcefully articulated the potential role of ELHS in the COVID-19 response: ELHS was uniquely able to get answers about best practices for epilepsy care during the pandemic. This leader extended her vision to argue that the findings needed to be shared ("And then we need to disseminate...") and that a case needed to be made that ELHS's way of working was "the way to work" in a setting of crisis. As I discuss in the following section, the way of working that this leader had in mind was to use principles of improvement science, namely plan-do-study-act testing, taking the practice guidelines being developed by epilepsy professional associations and testing them in actual clinic settings to see what worked.

4.2.3 | Improvement is a learning network's contribution

The novel challenges presented by COVID-19 made it difficult to know how to respond. Indeed, as one leader stated during a leadership discussion in March, "nobody has a playbook for this." However, improvement science fundamentally provides a method for producing a playbook, and one ELHS leader was able to convincingly argue that improvement was the logical way for ELHS to contribute in the environment of uncertainty created by COVID-19:

I just see this, you know, we're playing this game of Groundhog Day—except we should call it Groundhog City—where we see the same crisis developing [in] one city after another and we need to start getting ahead of this. So, if we can start piloting some of these things in places that aren't severely affected yet, so that when we are severely affected, we can actually maintain patient safety and continue to provide the services we need to provide, that would be phenomenal.

This leader articulates the potential of improvement science for maintaining patient safety and continuity in care. In response to these discussions within the leadership team, ELHS rapidly established a telemedicine working group, and members of this working group began developing and testing specific interventions, such as a telemedicine visit checklist for patients, within a few weeks of the group forming.

As ELHS executed on their predisposition to act, improvement and sharing went hand-in-hand. For example, the participant packet

for the Spring Learning Session contained a worksheet advertising the Learning Network practice "steal shamelessly and share seamlessly." This sheet contained blanks to jot down notes about what other sites were doing and a spot to credit the "Site I'm stealing from." In keeping with the ethos of improvement science, messages like these normalize the value and practice of sharing and testing, so that what seems to be working for one network site can be adopted in or adapted for one's own environment.

While these aspects of ELHS's culture can be described as they became salient in ELHS's response to COVID-19, ELHS is not an island. ELHS's culture of acting, sharing, and improving was shaped by their participation in a broader network of networks hosted by the Anderson Center for Health Systems Excellence, where specialists have crafted a theory of improvement and the curriculum to implement it. In this way, studying ELHS grants us insight into the broader culture of this network of networks that has adopted and contributed to the Anderson Center's approach to building Learning Health Systems.

4.3 | Mundane infrastructural elements help a network do its work

Finally, I return briefly to the notion that infrastructures are composed of mundane yet important elements that help a network do its work. The infrastructural elements I have described in the sections above—including the newsletter, the monthly all-network calls, the Learning Session, and the collaborative workgroup structure—can be harnessed as neutral vehicles for targeted content. This means that the same infrastructure that has been used to standardize seizure documentation can be used to respond to changes in epilepsy care due to COVID-19. The infrastructural elements of the network enabled the leadership team to share information with the network sites, the network sites to share information with each other, and the network sites to share information with both the network leadership and the many stakeholders who are participating in epilepsy care at network sites. In this way, the network accomplishes its iterative work of testing and sharing discrete interventions into epilepsy care.

5 | DISCUSSION

The goal of the research presented here has been to identify and describe Learning Network infrastructures in the interest of theory-building and development of the field of Learning Health Sciences. Within ELHS, the case example elaborated in this work, there was a shared understanding that the network infrastructure could be used for many purposes. By examining the actions and discourses of ELHS network leaders as they responded to COVID-19, it is possible to identify resonances with the theoretical approaches to infrastructure within Science and Technology Studies, and to lay out some of the scaffolding resources that STS can bring to the study of Learning Health Systems. Although a single-site case study of a small

organization necessarily has limited generalizability, situating the findings within a strong theoretical tradition in order to advance the foundations of Learning Health Sciences as a discipline is an important contribution.

As I have shown, network values and practices make certain courses of action logical during a crisis response. The specific values and practices that I highlighted were action, sharing, and improvement. Drawing on discussions among ELHS leaders and between the ELHS Leadership Team and the network members, I have shown that sharing is a fundamental value in ELHS. It was therefore considered a logical use of the network to employ the existing ELHS infrastructure to gather, circulate and distribute knowledge about a new problem of interest. Moreover, because improvement science is a fundamental framework in the network mindset, it became logical to want to do more than just share knowledge; knowledge sharing has a purpose—to both circulate best practices and report failures.

The case of ELHS has lessons for Learning Health Systems broadly that move the analysis beyond the findings reported above. First, it is important to build an infrastructure before it is needed. If a group has an infrastructure before a crisis hits, the group can use that same infrastructure to help respond to the crisis. Second, ELHS leaders were adamant that ELHS should not duplicate any work that was already being done by another group in the epilepsy community. The lesson here is to identify the contribution a group is best suited to make and to execute on it. For ELHS, this was the application of improvement science techniques to test potential best practices promoted by member sites and national epilepsy organizations. Finally, a third lesson is to not underestimate the mundane elements of infrastructure that are crucial for accomplishing a group's work. Once those elements are known, they can be put to work. This is a strong argument for building infrastructures, and by pointing to examples of infrastructure that are mundane and overlooked, I hope to draw attention to existing infrastructures so that their potential can be put to use.

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CONFLICT OF INTEREST

The author has no conflict of interest to declare.

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