Tell it Like it Seems: Challenges Identifying Potential Requirements of a Learning Health System

Allen J. Flynn
School of Information
University of Michigan
aflynn@umich.edu

Johmarx Patton
Medical School
University of Michigan
jepatton@umich.edu

Jodyn Platt
School of Public Health
University of Michigan
jeplatt@umich.edu

Abstract

This paper provides a review of some previously identified requirements of a learning health system, a post hoc analysis of narrative artifacts describing a learning health system, and some new potential requirements of a learning health system. Engaging a transdisciplinary group of researchers and health care practitioners, we used a method of group conceptualization to elicit potential requirements of a learning health system. Several unresolved challenges of creating and using narrative stories, diagrams and storyboards to elicit and share the potential requirements of a learning health system amongst a diverse group of researchers are discussed.

1. Introduction

The United States health system has been in an administrative crisis for two decades or longer. The overall cost of the health care services provided requires the nation to borrow and incur debt. Despite recent expansions in health benefits for many Americans, basic, affordable, preventive care with known beneficial effects remains unavailable to millions of people.

To end the crisis of American health care, the variability of outcomes from acute care must be diminished, individuals must change their health behaviors, and gaps in providing preventive care must be closed. To achieve these objectives, the health system needs to improve its ability to generate and apply existing and new knowledge. A “learning health system” that continuously refines and applies best practices has been envisioned. A learning health system would continuously improve its capabilities to select and execute useful procedures, to inspire worthy health behavior changes, and to identify and apply beneficial preventive measures. In general terms, what a learning health system must do is clear.

The problem is that the detailed requirements for a learning health system are unclear. To build a learning health system, it is necessary to conceptualize and describe its requirements in a clear, practical manner. F What a learning health system is must first be determined, and then its specific requirements must be identified. Once identified, the requirements of a learning health system must come to be understood by a huge and diverse audience. Only then may attempts to build the system be undertaken. Progress is being made to identify requirements for systems that generate new knowledge from big data repositories. However, the challenges and requirements for systematically disseminating and acting on new knowledge routinely derived from big data are not as well understood.

The audience of learning health system stakeholders is extensive. It includes a transdisciplinary community of scientists who must determine how to model, develop, deploy, and evaluate the system. For our project, dozens of scientists were assembled to do research about a learning health system. The work focused mainly on the dissemination and use of knowledge once it has been generated. The community of scientists informed, and was informed by, an ongoing learning health system conceptualization and requirements identification process. The community received, reflected on, and critiqued several kinds of learning health system representations and artifacts involving a variety of system requirements.

This paper describes early work of exploring, capturing, and communicating emerging learning health system concepts and potential requirements. Three research questions were addressed:

1. According to the scientific literature, what are some of the anticipated requirements of a learning health system?

2. What types of potential new requirements of a learning health system can be generated by using narrative artifacts to tell stories and prompt sharing of individual conceptualizations of the system and its requirements within a transdisciplinary scientific community?

3. What are some challenges of using narrative artifacts and story-telling techniques to elicit potential
2. Background and significance

A learning health system has been described as a solution to the problem of slow health knowledge dissemination. In this section we briefly recount that problem and the fundamental requirement for a learning health system to accelerate knowledge dissemination. Next we mention some potential benefits of a learning health system. Given these potential benefits we believe that work to realize a nationwide learning health system is worthy. Lastly we suggest why efforts by diverse scientific communities to conceptualize ultra large-scale systems and identify their requirements are important and deserve attention.

2.1. Health knowledge dissemination is too slow

There are seven competing motivations in our health system. They are to provide care; insure individuals and pay for care; educate health professionals; understand human health and disease; develop new treatments; understand public health; and educate all members of society about health. Each of these seven motivations is complex in isolation. Together these motivations combine to form a massive health system that incorporates almost 20% of the U.S. economy. Yet each motivation has distinct types and constellations of organizations, professionals, sellers, and consumers; and each one operates in a somewhat separate regulatory and policy environment.

Knowledge gained within any of the seven health system motivations needs to be shared, coordinated, and applied within the contexts of the other motivations for the overall health system to function well. When any or all of these processes are stymied, the whole health system may falter.

Two closely related health system motivations are to understand human health and disease and to provide care. Data suggest that new knowledge about health and disease is not incorporated rapidly enough into patient care decisions. The number of biomedical journal articles published per year has quadrupled since 1970. Practicing healthcare professionals read about one new journal article every day, yet this amount of reading covers only 0.1% of the published biomedical research output. Widespread use of the knowledge from trustworthy, landmark studies has been shown to take ten years or longer. Inadequate care results from existing limits on the rate of knowledge dissemination. For example, Americans are receiving only half of the acute, chronic, and preventive care measures recommended by established clinical guidelines.

Knowledge dissemination between the other motivations in the health system is also too slow. The health system’s ability to transfer knowledge about health and disease to the public is inadequate. Low health literacy persists and is associated with health disparities between subpopulations. Instructors of health professionals are concerned about limits to rote knowledge dissemination in education.

2.2. Intended learning health system benefits

A learning health system is generally intended to improve decisions that are made throughout the health system by informing them with actionable knowledge. Necessary safety benefits are intended from a learning health system. The safety record of the existing health system over the past thirty years is poor. In many instances we have the procedural knowledge needed to make the health system safer but lack the organizational knowledge to consistently and reliably apply safe procedures. A learning health system is intended to combine and disseminate procedural and organizational knowledge in ways that assure widespread safety improvements.

Economic benefits are intended from a learning health system. It has been estimated that 15% to 30% of health spending in the United States is wasted. This waste has been attributed to the health system’s inability to routinely increase the value of services rendered. Milstein foresees a learning health system as an adaptive one capable of optimizing health value through “continuously examining current clinical workflows” in order to find and adopt “new work methods” that provide optimal value for clients.

A learning health system for the United States should improve the health and well being of all Americans by assisting everyone to learn how to maintain their own health and the health of their kin. This broad intention honors the role of each individual as a health decision-maker. In a democratic society, decisions to adopt healthy behaviors can be officially encouraged but absolute compulsion must be rare. A learning health system is intended to help individuals
to freely evaluate options as they make health decisions.

A learning health system should also bring beneficial changes to the information environments of health workers. Today health workers have chaotic information environments.\(^{19}\) Difficult problems with health information include overload, scatter, missing and unstructured data, and conflicting or erroneous sources.\(^{19}\) While a learning health system is specifically not intended to organize all health data for its users (electronic health records and other systems exist for that purpose), a learning health system is intended to “wash out” erroneous or speculative information over time and to replace it with reliable knowledge that can be immediately acted upon.

Summarizing, there are several intended benefits from a learning health system: improved safety, greater value from services rendered, better individual health, and a less chaotic health information environment. To realize these benefits better decisions will have to be taken throughout the health system.

### 2.3. Need for transdisciplinary scientific activity to create a learning health system

The complexity of a learning health system can be understood in terms of its scale and scope. A learning health system has to generate and disseminate knowledge amongst the seven motivations in the health system. Thus it is an ultra-large-scale system. Regarding scope, a learning health system must span a variety of contexts and support decision-making about individual health, organized health services, and regional or national public health. Given its scope and scale, we argue that only a transdisciplinary scientific approach to the research and development of a learning health system will suffice to enable its construction.

The complexity of a learning health system might also be understood in terms of the number of processes and subprocesses involved in the system. A system capable of continuously collecting and analyzing health experience data, generating and packaging new knowledge, and then distributing the new knowledge to all interested takers just in time for decision-making involves many processes. Yet, summaries of the processes involved may hide the true complexity of a learning health system. Potentially overlooked are a host of unresolved epistemic, social, political, technical, cognitive, informational, educational, and behavioral issues that directly pertain to the modeling and development of a learning health system.

During a workshop sponsored by the National Science Foundation (NSF), 108 research questions about a learning health system were generated by a group of scientific experts.\(^{30}\) These research questions were organized into four categories: 1. Trust and Value, 2. Economic Sustainability and Governance, 3. An Adaptable, Self-improving, Stable, Certifiable, and Responsive System, and 4. A Capability to Engender a Virtuous Cycle of Health Improvement. These four categories reflect the diversity of scientific disciplines represented at the workshop.

Successful research to address the questions raised at the NSF workshop will have to be transdisciplinary research. Scientists from the engineering, social, and health sciences will have to form new teams that transcend traditional disciplinary boundaries.\(^{21,22}\) Here is an example question from the NSF workshop’s list:

> “How can a learning health system be designed, engineered, and operated as a self-defending and self-repairing system for purposes of protecting individual and institutional privacy and the integrity of data and knowledge against malicious attack and accidental disclosure?”\(^{20}\)

In this one question, whereas the engineering sciences are mentioned explicitly, the social sciences and the health sciences are clearly also involved. The need to coalesce transdisciplinary scientific activity is thus apparent. To begin to address research questions like this, we initiated a series of efforts to further conceptualize a learning health system and its potential requirements within a university where these and other related disciplines are represented.

Here we report several efforts to assess and expand the common ground for communicating about a learning health system and its potential requirements amongst a transdisciplinary group of scientists, with a special emphasis on the systematic dissemination and use of knowledge. This paper describes a method of iterative conceptualization and requirements elicitation used to help coalesce transdisciplinary scientific activity around the problem of slow health knowledge dissemination and the proposed solution of a learning health system. We believe this work is significant in part because ultra-large system project teams need to negotiate and settle upon system requirements through collaboration and sharing across multiple scientific disciplines with different research traditions.

### 3. Methods

Among the teams within our project the authors comprise a small team of three researchers whose role was to develop materials to describe changing ideas about what a learning health system is, what its requirements might be, and how a learning health system infrastructure might function. Given our team’s
purpose, we were nicknamed the “Go Team.” The Go Team had three tasks. The first task was to read and study select literature about a learning health system. The second task was to develop written artifacts describing a learning health system, its potential requirements, infrastructure, and uses. The third task was to iteratively enhance or refine the written artifacts developed by incorporating evolving concepts and newly identified potential requirements for a learning health system.

The work of the Go Team began by reading several articles about the learning health system concept. Later, the team undertook a limited literature review to identify and compare published definitions or descriptions of a learning health system and to examine the system requirements implied by these definitions.

The Go Team started its second task by drafting three narrative scenarios, or user stories, to describe specific uses of a learning health system. Then, using feedback on the narrative scenarios, the Go Team participated in the development of several explanatory diagrams. Finally, the narrative scenarios and diagrams together evolved into a storyboard artifact that depicted and described a series of learning health system interactions with users over an 18-month time frame.

Iterative improvement of the artifacts occurred at two levels. At a higher level, the artifact forms were iterated based on feedback from the scientists participating in the project. The forms changed from strictly narrative scenarios, to abstract diagrams, to storyboards that combined narrative content with diagrams in a time series. At a lower level, changes were repeatedly made to the content of all the artifacts. In all cases, artifact drafts were circulated, feedback was gathered, new ideas were incorporated, and updated drafts were circulated again.

We essentially executed an iterative group exercise to map two conceptual spaces. The first conceptual space map entailed concepts about what a learning health system is. The second conceptual space map entailed the requirements of a learning health system.

According to Gärdenfors and Warglien, conceptual spaces can be used to model actions and events. In conceptual spaces theory, a conceptual space is “framework for representing concepts.” A conceptual space for a concept has some number of psychological quality dimensions sorted into domains. Each domain represents a commonality amongst one or more quality dimensions. All of the quality dimensions of a conceptual space may not be known.

For our purposes, what is most relevant from conceptual spaces theory is that concepts are dynamic entities subject to progressive updating in the minds of human agents. Conceptualizations are individualized, dynamic, and seemingly true (but never true in the manner of a mathematical proof). The process of collaborative conceptualization is socially mediated but it ultimately relies on individual iteration on the quality dimensions pertaining to a conceptual space. Our work on the Go Team was in part to establish and maintain a dialectic about the learning health system within our scientific community in order to elicit ideas.

The work of the Go Team was an effort (a) to highlight for our group of diverse scientists potential concepts and requirements that may pertain to a learning health system and (b) to assess the apparent level of agreement regarding the highlighted concepts and potential requirements amongst community members. The Go Team catalyzed a collaborative, iterative conceptualization process. This process was dynamic and involved many individuals. The success criterion for this work was the discovery of new potential requirements for a learning health system, and especially those related to systematic knowledge dissemination and utilization.

The methods used to address our three research questions included a literature review to identify learning health system definitions, development of several types of artifacts to help with conceptualization of the system and its potential requirements, and a post-hoc analysis of three types of artifacts used in our collaborative conceptualization process.

3.1. Literature Review

Starting with several “seed” articles, a process of backward chaining using the references in published articles was conducted to identify additional articles with definitions or descriptions of a learning health system. In addition, a report from the Institute of Medicine from 2012 was reviewed.

3.2. Narrative Scenario Artifacts

Work began by writing and circulating narrative scenarios describing interactions with a learning health system and highlighting a few potential system requirements. In the scenarios, various fictional characters interacted with a learning health system in ways that ultimately resulted in individual learning.

The general form of each narrative scenario was three to five pages of prose with five sections: a problem statement, a description of the utility of a learning health system as demonstrated in the scenario, a description of the process of stakeholder learning arising from interactions within a learning health system, a summary of the scenario, and references. These five sections were selected to communicate the
essence of a learning health system to a diverse audience of scientists.

After the general form and format for the narrative scenarios were determined, each member of the Go Team independently authored a scenario. Each scenario focused on a different set of stakeholders (public health officials, clinicians or patients) and on a different disease domain (asthma, cognitive impairment or human immunodeficiency virus).

Once written, the three narrative scenarios were circulated amongst the members of the project and discussed at team-level meetings and at larger, project-wide gatherings. As the Go Team received feedback and suggestions for improvements, updates to the content, layout, and design of the narrative scenarios were made, and additional drafts were circulated again to project members.

3.3. Loop Diagram Artifacts

As our process continued, several themes emerged from the feedback about the three narrative scenarios. Important aspects of a learning health system were hidden by the details of the stories in the scenarios. The scenarios implied a simple linear path for learners within a learning health system. However, a complex learning interaction was more in keeping with what the project scientists actually envisioned.

When the themes from the feedback were discussed with the project leadership, a new diagram, the “loop diagram”, was generated and iterated upon by several project members. When a version of the “loop diagram” describing a learning health system in the abstract was settled upon by project leaders, the Go Team and other members of the project began working to articulate the concept of a learning health system using the loop diagram.

The loop diagram was shared with all project teams and discussed in detail at team meetings. To check for conceptual alignment or misalignment, the loop diagram was also explained and explicitly discussed at several retreats attended by many researchers. The questions and comments received during and after these sessions provided the Go Team with insights about the degree to which the loop diagram and its concepts were being incorporated into the project members’ own conceptualizations of what a learning health system is, and what its potential requirements are. After some improvements were made, the loop diagram came to be used in a variety of project artifacts to describe a learning health system and its functions, and thereby to suggest some of its key requirements.

3.4. Storyboard Artifacts

Eventually the Go Team was asked to combine a written prose form, like that of the narrative scenarios, with diagrammatic forms, like the loop diagram. The Go Team responded by creating a hybrid storyboard form.

A storyboard is a series of character-based drawings that may also include instructions, directions, and written dialog. It was hoped that a storyboard would communicate the dynamic nature of a learning health system in action. The Go Team sought to simultaneously communicate the learning that takes place among those who interact with a learning health system and the infrastructure needed to support the system.

The Go Team developed a storyboard for a hypertension use case. Word processing and illustration software were used to create the hypertension storyboard. A second storyboard for a use case of refractory pancreatic cancer was later created.

Feedback on the storyboards was collected and used to generate new storyboard drafts intended to convey refined conceptualizations of a learning health system, its infrastructure and corresponding requirements.

After four months of use, the project leadership determined that the hypertension storyboard needed to be condensed and clarified. A redesign process led by the Go Team was begun to update the content and improve the visual design of the storyboards.

4. Results

4.1. Descriptions of a learning health system and the requirements they imply

Two fundamental requirements of a learning health system can be inferred from Etheredge’s question, “How much faster can we learn?” A learning health system must demonstrate faster knowledge dissemination resulting in faster learning.

Several detailed descriptions of a learning health system are reviewed next. Additional requirements of a learning health system are noted in italics.

One description says a learning health system uses computer, information, and network technologies to afford communication and tailored advice-giving; experience data capture; health surveillance and evaluation; and knowledge generation. A learning health system is thus an instrument of cyclical continuous learning akin to continuous quality improvement programs in manufacturing. Notable here are system requirements of continuous communication,
formulation and broadcasting of advice, accumulation and organization of evidence, and generation of new knowledge. Others similarly emphasize related requirements for cyclic, iterative learning, integration with existing information systems, and support for health care work processes.

Taking the idea of a learning health system as a platform for continuous quality improvement a step further, the Institute of Medicine’s actual definition of a learning health system reads:

A learning health care system is one in which science, informatics, incentives, and culture are aligned for continuous improvement and innovation, with best practices seamlessly embedded in the care process, patients and families active participants in all elements, and new knowledge captured as an integral by-product of the care experience.8

The IOM suggests that the learning health system is a sociotechnical one. In part a learning health system must align incentives and culture for continuous improvement. For patients and families to be active participants in “all elements” of a learning health system the system must be patient-oriented.

Friedman and Rigby have described a federated learning health system15. In their model, standardized health experience data for individuals and populations are moved from points of collection to various “trusted investigative centers” where they are stored, aggregated and made accessible for remote analysis to authorized agents.15 Valid samples are taken from these data and reliable inferences about health are drawn systematically, resulting in a continuous flow of new population-level knowledge. A federated system is thought to be necessary to preserve some measure of autonomy for participating organizations in their relationship to a learning health system. A federated system potentially affords workable mechanisms for distributing control over health data and its use.

Policy and information retrieval requirements also pertain to a learning health system. Friedman, Wong, and Blumenthal foresee a nationwide “highly participatory” rapid learning health system16. They discuss the trustworthiness, voluntariness, and governability of a learning health system. They mention two other functions: accepting and generating a response to a query. A learning health system thus has requirements associated with information retrieval, including requirements related to system responsiveness and availability, and to the precision, and sensitivity of query results.

Research questions developed at an NSF workshop imply several more requirements of a learning health system including that it must be sustainable, adaptable, automated to a degree, and stable20.

Existing descriptive evidence indicates that a learning health system is a complex, ultra large-scale system with particular requirements. Some requirements are speculative. We believe not all requirements of a learning health system are known.

4.2. Requirements generated using artifacts

The narrative scenario artifacts told three short stories in step-wise, linear fashion. Each scenario highlighted an existing gap in health knowledge and raised a health question for which there was no definitive answer. Each narrative scenario described how a learning health system would generate and disseminate a new answer to the health question raised.

This narrative approach was found to be too simplistic. The requirements of a learning health system that were perceived in the evolving narrative scenarios were only those that would be apparent to knowledge recipients operating within a learning health system, and not those of most interest to the transdisciplinary scientific community participating in the project.

Requirements for a learning health system to be patient-centered, trustworthy, responsive, and available; and also to support stakeholder communication and accumulate data, were easily conveyed using the narrative scenario form. However, requirements of greater research interest such as the requirements for a learning health system to be federated, broadly applicable, adaptive, highly automated, sustainable, and governable were obscured or ignored in the narrative scenarios.

We found describing the infrastructure of a learning health system and its workings in prose to be very difficult. Perhaps the most difficult aspects to relate in narrative form were those that involved iteration or cycling. We realized that a scenario describing only one question being asked and answered by one learner did not convey continuous learning.

Another problem was that the feedback on the narrative artifacts focused more on the content of each scenario than on the requirements of a learning health system. Some project members asked for their scenarios were only those that would be apparent to narrative artifacts focused more on the content of each scenario than on the requirements of a learning health system. Some project members asked for their narratives to be more explicitly mentioned. Others suggested refinements to improve the plausibility or real-world fidelity of the scenarios. Concerns were raised about patient privacy and data security, issues that were perceived by the project leadership as important but somewhat peripheral to modeling a complex ultra large-scale learning health system.
Ultimately five aspects of a learning health system that were found to be difficult to capture and communicate in the narrative scenarios were identified:

1. **Iteration**: The iterative, continuous learning dynamics of a learning health system
2. **Timeframe**: The time frame for user learning in a learning health system
3. **Scope**: The scope of a learning health system and its infrastructure
4. **Novelty**: Differences between a learning health system and existing clinical decision support systems
5. **System science questions**: Issues most germane to grand challenges in system science

Discussions of difficulties encountered in attempts to describe a learning health system led to the articulation of a loop diagram to help conceptualize a learning health system in functional terms (Figure 1).

![Figure 1. Learning health system loop diagram](image)

The diagram depicts the afferent (left/blue) and efferent (right/red) sides of a “learning loop.” Starting at the lower left corner, experience data is assembled. Next these data are analyzed on the left side of the loop, and new findings (or knowledge) are generated. New findings are interpreted at the top of the loop. If new findings are appropriate to disseminate, they are formulated as actionable knowledge and communicated to user-participants as advice. Next, practices are changed based on the new findings and, finally, at the bottom of the loop, more experience data can be shared and the loop may repeat again.

The loop diagram shows data being transformed into new knowledge and new knowledge being disseminated and applied to decisions in the health system, resulting in opportunities to collect additional data as practices change.

The results from our use of the loop diagram in the project were mixed. The loop diagram was an improvement for conveying iterativeness and some aspects of the scope of a learning health system, yet there were essential requirements, such as requirements for automation and information retrieval, which were not clarified by the loop diagram.

The two-sidedness of the loop diagram did assist in bringing forth some additional, potential learning health system requirements. In particular, several potential requirements associated with the efferent (right/red) side of the loop became clear. These included requirements for an interpretive function to vet and validate new knowledge, for advice formulation and broadcasting, and for capturing data at the point of decision-making as practices change.

Difficulties conveying learning health system requirements using narrative scenarios or the loop diagram prompted the development of a hybrid artifact form combining narration with diagram, the storyboard form (Figure 2).

The storyboard form permitted the Go Team to design an artifact to explicitly convey various learning health system requirements, including requirements associated with system interaction, system infrastructure, and various other key properties of a learning health system.

The storyboards include four rows or “lanes” for depicting system functions, describing individual activities, depicting population views and data, and describing the work activities associated with a learning health system (Figure 2).

Each panel in a storyboard is associated with a particular moment or moments in time.

Feedback from project scientists on the storyboards varied. Real-world fidelity persisted as a challenge to the acceptability of the storyboards. After requests for more detail were addressed, some conceptual feedback was collected. An emerging learning health system requirement for analytical rigor was suggested. Another emergent requirement identified was to support users as they shift between individual and population level functions within a learning health system.

Although the storyboard form conveyed multiple learning health system requirements in one artifact, still the majority of the previously identified requirements were not well communicated using a storyboard. In particular, certain system level requirements such as a requirement to be sustainable and governable remained difficult to convey.
Figure 2. A storyboard panel

This figure shows one of the twenty-eight panels in a learning health system storyboard about hypertension treatment.

Problems associated with the use of all three artifact forms to facilitate collaborative iterative conceptualization and to elicit potential learning health system requirements included representing time in an acceptable manner and reader distraction due to “unrealistic” details. The challenge of representing “systemness” or system properties and corresponding system requirements by using these artifacts was not completely overcome.

To summarize these results, a table of learning health system requirements based on the literature review and the collaborative conceptualization process is provided (Table 1).

<table>
<thead>
<tr>
<th>Requirement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Faster knowledge dissemination</td>
</tr>
<tr>
<td>Faster learning about health</td>
</tr>
<tr>
<td>Support communication amongst participants</td>
</tr>
<tr>
<td>Facilitate accumulation of experience data</td>
</tr>
<tr>
<td>Generate new knowledge</td>
</tr>
<tr>
<td>Formulate advice*</td>
</tr>
<tr>
<td>Broadcast advice*</td>
</tr>
<tr>
<td>Tailor advice messages to individual recipients*</td>
</tr>
<tr>
<td>Integrate with existing information systems</td>
</tr>
<tr>
<td>Support existing work processes</td>
</tr>
<tr>
<td>Permit public access to the system</td>
</tr>
<tr>
<td>Be patient-oriented</td>
</tr>
<tr>
<td>Operate continuously</td>
</tr>
<tr>
<td>Align user interactions with system goals</td>
</tr>
<tr>
<td>Accommodate various cultures</td>
</tr>
<tr>
<td>Support federated architectures</td>
</tr>
<tr>
<td>Be trustworthy</td>
</tr>
<tr>
<td>Support voluntary use</td>
</tr>
<tr>
<td>Be governable</td>
</tr>
<tr>
<td>Be sustainable</td>
</tr>
<tr>
<td>Maintain a minimum level of responsiveness</td>
</tr>
<tr>
<td>Optimize query response precision</td>
</tr>
<tr>
<td>Optimize query response sensitivity</td>
</tr>
<tr>
<td>Demonstrate social utility</td>
</tr>
<tr>
<td>Support iterativeness learning</td>
</tr>
<tr>
<td>Be generalizable to many types of questions</td>
</tr>
<tr>
<td>Adapt to changing needs</td>
</tr>
<tr>
<td>Automate repetitive processes</td>
</tr>
<tr>
<td>Maintain a minimum level of stability</td>
</tr>
<tr>
<td>Provide for a virtuous cycle of health improvement</td>
</tr>
<tr>
<td>Demonstrate analytical rigor*</td>
</tr>
<tr>
<td>Interpret, vet, and validate new knowledge*</td>
</tr>
<tr>
<td>Support shifts between individual and population level functions*</td>
</tr>
<tr>
<td>Trigger data capture at the moment of decision making when knowledge is applied*</td>
</tr>
</tbody>
</table>

Table 1. Some learning health system requirements (* indicates an emergent, potential requirement)

5. Discussion

This paper offers three contributions. First, system requirements are drawn from several definitions of a learning health system. Second, a method of requirements elicitation using descriptive, narrative artifacts about a complex socio-technical system is discussed. Third, the qualitative results of applying the method to elicit and generate potential requirements for a learning health system are shared and analyzed.

Various requirements of a learning health system may be more or less obvious to scientists trained in
different fields. For engineers, requirements related to adaptability, automation, and trust may quickly come to mind. Health policy researchers may easily perceive requirements related to system governability. As system users, patients, family members, and health professionals may each perceive different requirements for specific types of information to be provided to them. Eliciting, synthesizing, and collecting many perspectives on system requirements was our goal.

The storyboard artifact form afforded the most opportunities to respond to our transdisciplinary community of scientists by balancing multiple perspectives on the essential requirements of a learning health system in a single document.

Regardless of the type of artifact used to describe a learning health system and its infrastructure, effective communication of some important system requirements continues to elude us. Infrastructures tend to be invisible until they fail to work properly. When describing the workings of a learning health system we assumed that stable computational, data storage, and networking capabilities would simply be available. Over time these assumptions were made more explicit.

Describing time frames, iterative learning, recursive processes, and complex interactions amongst the various entities within a learning health system was the most difficult part of our assignment. Through trial and error we were able to improve in our ability to describe iterative learning. Attempts to describe more complex system behaviors were not very successful.

Having made some headway, perhaps our most important findings are the host of learning health system requirements that we gleaned from other sources and augmented by analyzing how several different artifacts used to describe a learning health system evolved within our project.

5.1. Limitations and future research

Our work informs a growing movement to create a health information system that not only analyzes big data, but also generates and implements actionable knowledge, and continually captures more data in a cycle of continuous learning. While the project engaged a large and diverse, transdisciplinary group of stakeholders, not all success-critical stakeholders were involved. Further engagement with a broader range of potential users including providers, the general public (patients), and other researchers would help validate the system requirements identified in this paper. Replication of a similar process in other contexts would also inform the definition of success-critical stakeholders, which could improve the efficiency of implementing learning health systems across the nation and the globe. Future research should compare socio-technical systems within and outside of the health industry context (e.g., banking or transportation systems) to identify areas of convergence and divergence amongst ultra-large, complex, socio-technical systems.

6. Conclusion

The lyrics of the George Davis and Lee Diamond song, “Tell It Like It Is”, assume that the hearer truly knows how it is. We believe that in the context of transdisciplinary complex system projects, scientists’ conceptualizations of relevant concepts, properties, and requirements are individualized and need to be stated and considered openly by project participants. When sharing our conceptualizations of problems, solutions, and relevant research questions, it is advisable to invoke this modified imperative, “Tell it like it seems.” For an individual scientist to describe a key concept within a group “like it seems to them” acknowledges the uncertainty that pertains to the psychology of conceptualization, and also provides for potentially improved communication, sharing, and group-wide understanding.

With respect to the concept and requirements of a learning health system, having worked for a year to examine and communicate them using various artifacts we nevertheless can still only tell about how a learning health system seems. However, by telling how it seems we have determined some additional requirements of a learning health system beyond those previously recognized, and we believe that several newly identified requirements may be essential.

In this case transdisciplinary scientific activity did coalesce around the artifacts used to communicate concepts related to a learning health system to some degree. We anticipate that additional research output in the areas of health policy, information, and computer science will reflect the collaborative iterative conceptualization of a learning health system and its apparent requirements within our project and research community.

7. References


