

Vinson Alexandra H (Orcid ID: 0000-0002-9062-7899)
Seid Michael (Orcid ID: 0000-0001-9773-9263)
Hartley David M (Orcid ID: 0000-0003-2589-2538)

Toward an Ontology of Collaborative Learning Healthcare Systems

Alexandra H. Vinson¹, Michael Seid^{2,3,8}, Breck Gamel⁴, Shehzad Saeed⁵, Brandy Fureman⁶, Susan C. Cronin², Katherine Bates⁷, David Hartley^{3,8}

¹Department of Learning Health Sciences, University of Michigan

²Division of Pulmonary Medicine, Cincinnati Children's Hospital Medical Center

³James M Anderson Center for Health Systems Excellence, Cincinnati Children's Hospital Medical Center

⁴Co-Chair, Network Leadership Team, Cystic Fibrosis Learning Network

⁵ Department of Medical Affairs, Dayton Children's Hospital

⁶ Mission Outcomes Team, Epilepsy Foundation

⁷Department of Pediatrics, C.S. Mott Children's Hospital, University of Michigan Medical School

⁸Department of Pediatrics, University of Cincinnati College of Medicine

Corresponding author:

Alexandra H. Vinson

Department of Learning Health Sciences

University of Michigan

1111 E. Catherine St, Ann Arbor, MI 48104

ahvinson@umich.edu

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ABSTRACT

Objective: To establish a basis for a domain ontology – a formal, explicit specification of a shared conceptualization – of collaborative learning healthcare systems (CLHSs) in order to facilitate measurement, explanation, and improvement.

Methods: We adapted the ‘Methontology’ approach to begin building an ontology of CLHSs. We specified the purpose of an ontology, acquired domain knowledge via literature review, conceptualized a common framework of CLHSs using a grounded approach, refined these concepts based on expert panel input, and illustrated concept application via four cases.

Results: The set of concepts identified as important to include in an ontology includes goals, values, structure, actors, environment, and products. To establish this set of concepts, we gathered input from content experts in two ways. First, expert panel methods were used to elicit feedback on these concepts and to test the elicitation of terms for the vocabulary of the Values concept. Second, from these discussions we developed a mapping exercise to test the intuitiveness of the concepts, requesting that network leaders from four CLHSs complete a mapping exercise to associate characteristics of their networks with the high-level concepts, building the vocabulary for each concept in a grounded fashion. We also solicited feedback from these participants on the experience of completing the mapping exercise, finding that the exercise is acceptable and could aid in CLHS development and collaboration. Respondents identified opportunities to improve the operational definitions of each concept to ensure that corresponding vocabularies are distinct and non-overlapping.

Discussion: Our results provide a foundation for developing a formal, explicit shared conceptualization of CLHSs. Once developed, such a tool can be useful for measurement, explanation, and improvement. Further work, including alignment to a top-level ontology, expanding the vocabulary, and defining relations between vocabulary is required to formally build out an ontology for these uses.

Keywords: collaborative learning health system, learning networks, ontology

INTRODUCTION

Collaborative Learning Healthcare Systems (CLHSs) are a promising approach to answering the National Academy of Medicine's call for a Learning Healthcare System (Institute of Medicine 2007). The CLHS approach has been replicated and has repeatedly demonstrated improvement in outcomes (Britto et al 2018, Donovan et al. 2010, Crandall et al. 2012, Anderson, et al. 2015). Based on these successes, we expect the number and diversity of CLHSs to increase; indeed, improving and scaling this model is one path to large-scale health and healthcare improvement. In order to improve and scale CLHSs, we need to have a "formal, explicit specification of a shared conceptualization" (Studer et al. 1998) – an ontology - of what we mean by CLHS. An ontology allows researchers and practitioners alike to learn faster from one another, thus advancing progress towards this goal. Ontologies are used commonly in medicine to define concepts and relations between them (e.g., ICD, SNOMED, UMLS), enabling wide scale use and reuse of information in clinical and research environments. Without a common framework, we will be hampered in measuring, explaining, and optimizing CLHSs.

An emerging literature is beginning to describe CLHSs. Britto et al. (2018) have described the network organizational architecture of Learning Health Networks, a type of CLHS, and Seid et al. (2020) have shown how the ImproveCareNow Learning Network increased the number of actors, the number of shared resources, and the tools for making it easier to form teams, consistent with an 'actor-oriented architecture' (Fjeldstad et al. 2012). Lannon et al. (2020) describe a network maturity grid that measures the maturation of the infrastructure and processes necessary to create Learning Health Networks, as one form of CLHS. Hartley et al. (2020) have developed a system for classifying, recording, and tracking engagement behavior in CLHSs, and, though not specific to CLHSs, Kaplan et al (2012) have developed a conceptual model to understand and optimize contextual factors affecting the success of a quality improvement (QI) project. Recently, Seid et al (2021) have described a theoretical basis of CLHSs, articulating them as complex adaptive systems and identifying potential mechanisms of action, and Vinson (2021) has explicated culture as a form of infrastructure in CLHSs.

Creating and developing measures of CLHSs is important for understanding the system-level qualities of CLHSs, including number of actors, amount of sharing, maturation of organizational processes, participant engagement, and quality improvement (QI) context. Focusing only on measurement, however, risks incomplete specification of the potential range of CLHSs themselves. How do we know what is important to measure? What are the key similarities and differences across CLHSs? What is and is not a CLHS? For that, one must develop a language for describing the abstract features of CLHSs. To our knowledge, such a set of concepts to define and describe CLHSs, with a common vocabulary for these concepts, does not yet exist. The primary motivation for this study, therefore, is to identify foundational concepts for the eventual specification of an ontology of CLHSs that transcends any specific network. Moreover, we began with an inductive, grounded approach, drawing on the expertise of CLHSs leaders to generate high-level terms and begin to populate vocabularies. In this way, the ultimate framework will arise from the elements of CLHSs activity that are salient to those involved. We use the term ontology to refer to the concepts, relationships, and properties of CLHSs. Our eventual aim is to summarize relevant concepts, define the vocabulary of these concepts, and

describe the meaning of those terms to arrive at a plain language specification that is understandable and useful to CLHS participants and to researchers studying different systems. To begin, we have proposed a set of concepts, solicited expert panel input on the appropriateness and comprehensiveness of these concepts, tested an approach to forming the vocabulary of one domain, developed an mapping exercise to begin populating the vocabulary of the other concepts with real-world examples, and gathered feedback on the usefulness of the mapping exercise. Our primary focus is on the process of developing an ontology, rather than presenting a completed ontology.

METHODS

Fernandez, Gomez-Perez & Juristo (1997) have described a methodology for developing ontologies, which they call the “Methontology” approach. The process has six steps: specification, knowledge acquisition, conceptualization, integration, implementation, and evaluation. In this paper, we have carried out a variant of this approach, using iterative cycles of discussion, analysis, and interpretation to support the Methontology process’ steps of knowledge acquisition, conceptualization, integration, and implementation. The following sections correspond to steps in the Methontology process (Fernandez, Gomez-Perez & Juristo 1997), mapping our procedure as we identified and tested high-level conceptual elements for an ontology of CLHSs.

In order to gather domain knowledge, we employed a focus group method to create an expert panel among our author team, which, being composed of CLHS members and closely affiliated researchers, represents a stakeholder group with deep expertise in forming, leading and growing CLHSs. Two expert panel discussions were designed to specify and conceptualize the high-level conceptual elements for describing common attributes of CLHSs. Authors AV and MS designed a semi-structured interview guide for each panel discussion and led the discussion. Each focus group convened virtually and was recorded and transcribed to facilitate analysis. Data were maintained by AV, who analyzed each panel discussion by organizing the conversation into a set of main topics, highlighting key features of the discussion for follow-up in the second panel.

The first expert panel was designed to identify a notional set of concepts for describing common features of CLHSs. The second expert panel was designed to elicit feedback on the completeness of the set of concepts identified for describing common features of CLHSs. At this stage of development, we did not identify a hierarchy of entities subordinate to the high-level concepts, but rather recorded candidates as “vocabulary” modifying each concept. In the future, it may be possible to inductively generate a hierarchy of entities within each concept, once each vocabulary has been fully populated. Therefore, a second goal was to develop techniques, described below, for eliciting the vocabulary associated with these concepts.

Finally, we tested our findings using a proof-of-concept mapping exercise, the “ontology tool,” during which leaders from four Learning Health Networks, a type of CLHS, contributed vocabulary to the conceptual elements based on attributes of their network.

Based on their participation in the work of developing the foundations of an ontology, participating in the expert panel discussions and mapping exercises, and their subsequent contributions to the manuscript, the expert panel members are included in the author team. This study was determined to be exempt from ongoing review by the Health Sciences and Behavioral Sciences IRB at the University of Michigan.

RESULTS

Conceptualizing the Ontology

Based on an analysis of the first expert panel discussion, we (authors DH, MS, AV) conceptualized an informal model of CLHSs based on the knowledge shared by practicing experts, which we subsequently introduced for discussion and revision during the second expert panel discussion. In the process, we observed that statements of a common structure could be constructed for each network represented by the expert panel members. Regardless of detail and specificity, descriptive statements involved basic types of information drawn from a small set of concepts. That set included high-level concepts common to different networks (Table 1).

During the second expert panel, authors AV and MS presented the draft version of the high-level concepts to the expert panel members, seeking their initial impressions and feedback on whether these comprehensively described the major domains of Learning Network activity and whether this set seemed original and not duplicative of other frameworks. We used the following prompt to begin a discussion about an ontology structure: *do you think that these categories fully describe the Learning Network or its activity, or are there other categories we would need to add?* As expert panel members considered the existing concepts and tried to apply them to their network, this elicited a series of questions and discussion about where elements of their network could be categorized. This discussion generated two additional concepts (Actors and Environment), which we subsequently included. One additional refinement that emerged from this discussion was that it was unclear where larger forces like policy and COVID-19 ought to be situated in an eventual ontology. At first, these were included as vocabulary under the “Actor” concept, but were subsequently moved to Environment. Another refinement was to define terms within Values as “rules of engagement” whereas values as aspirations (e.g., equity) would be placed in Goals.

We observed, for example, that each specific network had one or more statements defining network goals. Goal reflects the ends toward which network participant effort is directed. We also observed that networks have values shared by participants and groups of participants. Value reflects the principles underlying individual and group behavior. We noted that networks self-organize into different organizational and social structures (Structure), and that there is a spectrum of patterns of organization defining different structures. We found that a variety of

actors (Actor) were present in different networks, including individual actors (e.g., specific patients and specific healthcare providers) and group actors (e.g., patients, advocates, providers, researchers). We also observed a rich variety of environments in which networks existed. Environment describes the context that the network and sites are imbedded in, including not-for-profit holding companies, universities, hospitals, and healthcare systems. Environment can also include movements such as the maker/DIY movement or patient centered care movement, as well as forces external to the network that affect its functioning or outcomes, such as the COVID-19 pandemic, structural racism, health insurance coverage, external funding, and other forces. We also noted that networks produce various products (Product), such as improved outcomes, as well as information, knowledge, and know-how.

[TABLE 1 ABOUT HERE]

While additional high-level concepts did not crystallize during the expert panel discussions, we remain open to incorporating additional concepts as we discover that they are salient to the work of other CLHSs. For example, should engagement be a distinct, high-level concept or instead be related to set of vocabulary terms that is nested under Value? In developing and testing this set of concepts, items may be added to both the high-level concepts and vocabulary as CLHSs continue to develop and become more numerous.

Integration: Values Elicitation

During the second expert panel, we piloted a method for populating vocabularies using the example of Values. To do this, we used elicitation techniques in a focus group setting. We began by asking each expert panel member to think silently about their network's formally stated values, and then to share these values aloud or type them into the chat window. After values were elicited, expert panel members discussed consonances, identified informal values in their networks that were formally expressed by other networks' values statements, and explored the notion of a network community enacting a set of values.

We conceptualized the vocabulary as a set of nominal variables, allowing users to describe, using a standard set of high-level concepts, the CLHS in their own words. Therefore, we did not ask users to rate the degree to which a CLHS is consistent with a set of variables (e.g. 'On a scale of 1-10, rate to what extent patients are involved in your network'). By the end of the second expert panel discussion, we had generated a long list of values shared within, and in some cases across, the Learning Networks represented by the expert panel members (Table 2). We propose that this list serve as an initial population of the Value concept in our draft domain ontology.

[TABLE 2 ABOUT HERE]

While this list of values should not be considered a complete set that represents the values of every Learning Health Network, it is an indication of the range of values CLHS members associate with their networks and try to put into practice during network activities. Importantly, we were able to elicit these values effectively using focus group facilitation techniques, which can lay the procedural groundwork for populating the other domains of the ontology.

Implementation: Mapping Exercise

In order to test the salience of the high-level concepts, the feasibility of populating the vocabulary for each concept, and the acceptability of completing such an exercise, we asked domain experts to contribute vocabulary from their CLHS to each of the high-level concepts (see Table 3 for the version of the tool provided to participants).

[TABLE 3 ABOUT HERE]

In one case, authors AV and MS met with a network leader to complete this process; in another case, two members of one Learning Health Network filled out the tool and provided a short reflection on the process. In the two final cases, network leaders who were not participants in the expert panel discussions were asked to complete the mapping exercise, in order to test the context-dependence of the framework and tool. Results from the mapping exercise are included in the tables below (Tables 4, 5, 6 and 7).

[TABLE 4 ABOUT HERE]

[TABLE 5 ABOUT HERE]

[TABLE 6 ABOUT HERE]

[TABLE 7 ABOUT HERE]

We judged the feasibility of this exercise based on the reflection portion of the mapping exercise (see Table 3). We attended to whether the network members were able to complete the process with minimal questions or concerns. Representatives from two networks raised concerns about clarity, including how to choose items to add in each category and how to apply the operational definitions for each concept. Based on these reactions, we believe that further field testing is warranted, along with refined operational definitions to ensure that concepts are distinct and non-overlapping. Similarly, the reflection material gave us insight into the acceptability of the mapping tool and overall interest in an ontology. For example, one network leader said that having an ontology based on these concepts would be helpful for leaders to be able to compare their networks and learn from one another, a common network practice that could be better organized by a standardized model of presenting high-level network attributes. Another network leader remarked, “I’ve thought through all these characteristics of the learning community at one time or another, but never at the same time. It turned out to be a useful and defining exercise having it all together to view on one grid.” Overall, participating network leaders found the tool to be “fairly straightforward,” that having operational definitions clearly stated was helpful, and that the tool warrants further field testing to reduce the amount of interpretation of the operational definitions users of the tool must perform.

DISCUSSION

In this paper we describe initial steps in the development of an eventual domain ontology of CLHSs. We used two focus groups with network experts to develop the high-level concepts that may form the basis of an ontology of CLHSs. This initial description of common conceptual elements of CLHSs is a first step toward a common language for describing CLHSs more generally. Having a common language may be helpful in many ways, including generating a shared understanding of the CLHS structure of information, which describes both domains in the ontology and the relationships between domains. An ontology could also enable the sharing and reuse of knowledge between different networks, as well as explicitly identifying and labeling assumptions and gaps in knowledge (Noy & McGuinness 2001).

We anticipate that the fully populated domain vocabularies will be an important resource for newly forming Learning Health Networks as they become an increasingly comprehensive set of network activities, attributes and products. This is because an ontology can provide an abstract framework that organizes the metacognitive work of Learning Health Network design. In light of the goal to rapidly bring new Learning Networks online in the coming years, incorporating this ontology into the network design phase could help newcomers grasp their options for network activities and attributes. As one expert panel participant described, having this ontology, especially with the vocabularies populated by other existing LNs, would not so much be a “recipe” as it would be a “menu,” allowing new networks to see what their options are for network structure, actors, products, and so on. Such a framework might also facilitate partnerships and collaboration between and across CLHSs if commonalities are identified in one of the categories that might not otherwise have been apparent. In this way, the identification of common aspirations across CLHSs can promote the co-creation and sharing of resources and expertise. In addition, by creating this common framework of CLHNS, members of CLHSs can be better prepared to advocate for allocation of resources, such as finances, staff and space, from health system leaders.

Finally, an ontology may also offer a framework for including new areas of focus in CLHSs. For example, awareness of the importance of equitable healthcare, especially resource availability and delivery, is growing. If CLHSs develop new initiatives on equity, conceptualizing where such initiatives fit in the ontology, and the corresponding vocabulary, may help guide implementation and identify where institutional support is needed. Answering questions such as how equity fits conceptually (e.g., Environment, Value, Actor), and what products may be produced as resources, are useful for moving from the ideation to action phases of new initiatives.

The high-level concepts we generated and tested via our expert panel and mapping exercise help us gain insight into the choices CLHSs make as they form, how these choices manifest as network aspirations and achievements, and how network choices are shaped by the environment and resources the network has access to. In this way, developing a set of high-level concepts grants insight into the infrastructure of CLHSs.

Next steps toward defining a functional ontology include aligning the identified concepts with a top-level ontology such as Basic Formal Ontology (BFO) [Arp et al 2015] and defining hierarchical relations between concepts and vocabulary. BFO provides a set of relational constructs used widely in the biomedical sciences, so that utilizing BFO provides an opportunity for ensuring compatibility with other existing and potentially nascent ontologies in the biomedical domain. The high-level concepts identified above are candidates for continuant entities in BFO, and the identified vocabulary are related continuants in different ways, including hierarchically (e.g., inclusivity is a value). Additional work remains to be done to more formally assess whether different respondents interpret the concepts consistently, identify recommended vocabulary and more fully build out relations and hierarchies in more appropriate detail. Similarly, recording the ontology in a software platform (e.g., Protégé, <https://protege.stanford.edu/>) where it can be stored, revised, shared, and interacted with, will aid in both developing the ontology and making it available to users.

In this paper we have taken the initial steps to developing a set of high-level conceptual elements that may form a domain ontology, and we have developed methods for continuing this work. In particular, we have developed qualitative approaches for identifying concepts and vocabularies, seeking to ground our high-level concepts in the experience and expertise of Learning Health Network members. In addition, we have tested a method for incorporating other networks' characteristics and activities into the ontology via the "ontology tool" and mapping exercise. Having a common language of CLHSs, populated by a vocabulary drawn from extant networks, exposes the diversity of existing networks, can assist new networks in making choices in their developmental phases, and can alert evolving networks to possibilities for change. In the spirit of "sharing seamlessly and stealing shamelessly," networks – even mature networks – can learn from the successes of other networks and adapt to improve their own organization. In this sense, an ontology provides a "menu of choices," informing decisions to be made by new, emerging, and mature CHLSs alike. to generate knowledge about the pathways and attributes of successful networks.

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Conflict of Interest

Michael Seid is an inventor of intellectual property licensed by CCHMC to Hive Networks, Inc., a for-profit company that provides software and services to support learning networks.

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Table 1: Proposed ontology of Collaborative Learning Health Systems

GRAMMAR		VOCABULARY
Goal	what the network is trying to accomplish	* the vocabulary of <i>_goal_</i> may include terms for clinical health, QI/research, psycho-social health, engagement
Value	the network's rules of engagement	* the vocabulary of <i>_value_</i> may include terms for inclusivity, equality, coproduction, partnership
Structure	the network organization and relations	* the vocabulary of <i>_structure_</i> may include terms for leadership, relation to healthcare environment, maturity, repository for data/digital assets (commons), hardware, how the network is funded
Actor	who/what is participating in network activity	*the vocabulary of <i>_actor_</i> may include terms for people, animals, and other entities and objects that participate in the construction of relations within a network: patients, parents, advocates, healthcare providers, social workers, committees, panels, working groups
Environment	context that the network and sites are imbedded in	*the vocabulary of <i>_environment_</i> may include terms for the institutional, natural, cultural, or socio-political environment that shape the possibilities for constructing relations within a network: hospital, practice, university, company, external forces, policy, funding
Product	tangible outputs of the network	* the vocabulary of <i>_product_</i> may include terms for information/WINWIN, research data, innovations, network narrative (incl origin story), procedures

Table 2: Values elicited during expert panel discussion, duplicates represented in parentheses to show consonances

Values		
Co-production	Shared Learning (2)	Improving Life with those with CF
Growth	Data-based	Using QI skills
People-centered	People first	Innovation
Equality in coproduction	Generosity (2)	Achieving more together than alone
Laugh & have fun while we work	We collaborate: spirit of QI	Empathy (2)
Failure is the way we learn (2)	Contribution	Equity (3)
Shared Purpose	Collaboration	Embrace uncertainty
Transparency (3)	All teach, all learn (3)	Co-production with families
Lack of respect for the status quo	Share seamlessly and steal shamelessly	Respect for all colleagues and all ideas
Learning from Data	Respect for all	Focus on outcomes (2)
Relentless focus on outcomes	Distributed leadership	Who's at the table
Patients and families are the center of our work	We are a circle, not a hierarchy: we coproduce with our patients and families	

Table 3: Ontology Mapping Exercise

	Goal	Value	Structure	Actor	Environment	Product
[Network Name]						

Operational definitions:

1. Goal = what the network is trying to accomplish
2. Value = the network's rules of engagement
3. Structure = the network organization and relations
4. Actor = who/what is participating in network activity – includes inanimate objects
5. Environment = context that the network and sites are imbedded in
6. Product = tangible outputs of the network

Instructions: Please fill in the table to describe attributes of your network. You can use lists, short phrases, keywords, etc.

REFLECTION – Please take 5 minutes and write a paragraph about what it was like for you to fill this out:

Table 4: Mapping exercise for Cystic Fibrosis Learning Network

Cystic Fibrosis Learning Network	
Goal	Improve health outcomes, improve co-production, partner with Cystic Fibrosis Foundation (CFF) to innovate, co-production of care, co-production of quality improvement - Shared purpose, intrinsic motivation or build will
Value	Partnership, transparency, data-driven testing/quality improvement, quality improvement (QI) skills, equity of patient and family members, time pressure, Leaders help others to lead
Structure	Individual QI teams at CFF sites/institutions, with embedded Patient/Family Partner (PFP) on each team, with a focus of a triad (physician lead, QI lead, PFP lead); partnership with CFF. Network Leadership Team + workgroups, mentorship, snowflake model. Model for Improvement. Work is funded by CFF. Workgroups. IRB approval is already established (existing part of structure). iLabs. Strong support from operations team and Quality Improvement Consultants.
Actor	Clinicians, Patient & Family Partners (PFPs), CFF, experts and advisors, patients and families who are not PFPs, registry team, institution as entity with person-like qualities (especially for grants and permissions), members of other networks (as we learn at LNCC or through the literature and websites, we have borrowed heavily from other networks, e.g. by looking at change packages).
Environment	Institutions (care centers, etc.), honoraria and grants, COVID, time, trikafta, competing interests for time and thinking. CFLN teams are also members of Therapeutics Development Network, Success with Therapies Research Consortium, and Transplant Consortium
Product	Change packages, experienced leaders, engaged PFPs, publications, reliable clinical processes, innovations, rapid learning, build a culture of passion and curiosity, i.e. culture of improvement

Table 5: Mapping Exercise for ImproveCareNow

ImproveCareNow	
Goal	<ol style="list-style-type: none"> 1. Transforming the health, care and costs for all children and adolescents with inflammatory bowel disease (IBD) by building a sustainable collaborative chronic care network. 2. Enable/Empower patients, families, clinicians and researchers to work together in a learning health care system to accelerate innovation, discovery and the application of new knowledge 3. Achieve financial sustainability 4. Focus on health inequity, increase diversity and bridge the gap on disparities 5. Integrated Technology Platform 6. Continued focus on community engagement and patient centered outcomes
Value	Inclusivity, Honesty, Transparency, Community, Empowerment, Learning, Continuous Improvement
Structure	<ol style="list-style-type: none"> 1. Board of Directors 2. Executive Directors 3. ICN Staff 4. Anderson Center for Health System Excellence Staff 5. Community Council (represents community stakeholders with representation from each stakeholder group as listed in 6-17) 6. Physician Leadership Group (represents physician leads from selected sites) 7. Research Committee (reviews research proposals) 8. Parent Working Group (comprised of participating parents) 9. Patient Advisory Council (comprised of patients who are focused in developing patient facing tools as well as representing a patient perspective at various community fora) 10. Clinician Committee (comprised of physicians who determine and develop clinical and Qi focus for the network) 11. Data Management Committee (comprised of clinicians, parents, and patients and determine data- process, QI and outcomes measures-, tracking and reporting of these measures to the network) 12. Social Workers and Psychologist Working Group (focused on developing content and projects on mental health for the network participants) 13. Dieticians Work group 14. Coordinator Work Group-comprising of ICN/Anderson Center staff working with center coordinators for data related issues and updates 15. Nurses Work Group 16. Engagement Group (Stakeholders representative focused on improving community engagement and awareness work) 17. Regulatory Group (ICN and Anderson Center staff focused on regulatory (eg IRB) focused deliverables) 18. Diversity, Equity and Inclusion Committee(Network wide committee reporting up to the Board developing and focusing on DEI efforts for outcomes, leadership, and staffing)

<p>Actor</p>	<ol style="list-style-type: none"> 1. ICN executive leadership and staff 2. Contracted Staff including Cincinnati Children's Hospital Medical Center and others 3. Community stakeholders- physician leads, coordinators, dieticians, psychologists, nurses, parents and patients 4. Researchers including clinicians and health outcomes researchers 5. Industry partners 6. Foundations 7. Federal funding agencies (Agency for Healthcare Research & Quality, Patient-Centered Outcomes Research Institute)
<p>Environment</p>	<p>Technology Infrastructure support provided by Biomedical Informatics. Now pivoting to platform provided by HIVE Networks for Registry, Collaboration, Social Interaction, File Sharing</p>
<p>Product</p>	<ol style="list-style-type: none"> 1. Publications 2. Tools-These include patient developed and patient facing tools, Self Management Handbook, Visit planners, Growing up with IBD, Ostomy Toolkit, Shared decision making tool kit for surgery etc, etc 3. Information sharing tools like the every other week newsletter-DIGEST, LOOP Blog, CIRCLE newsletter for patients and families, etc etc 4. Quality Improvement educational modules 5. Continuing Medical Education and Maintenance of Certification credit for clinicians 6. Data and Population Management capabilities

Table 6: Mapping Exercise for T1D Exchange QI Collaborative (T1DX-QI)

T1D Exchange QI Collaborative (T1DX-QI)	
Goal	Improve clinical and patient reported outcomes for people living with Type 1 diabetes.
Value	<ol style="list-style-type: none"> 1. All learn and all share shamelessly 2. Every benefit when everyone participates 3. Give credit when due 4. Our work is about improving lives so we co-produce with patients 5. Nobody should be left behind; we must intentionally embed health equity in our processes and outcomes.
Structure	<ol style="list-style-type: none"> 1. Network was established in 2016 2. The Coordinating center is the T1D Exchange, a Boston based non-profit. 3. The network is funded by Helmsley Charitable Trust, a NY based philanthropic organization. 4. The Coordinating center has improvement coaches that meet with the team individually bi-monthly for benchmarking and improvement advice. 5. The Coordinating center hosts a bi-monthly collaborative call with Adult and Pediatric centers separately 6. There are joint learning sessions in the spring and fall.
Actor	<ol style="list-style-type: none"> 1. 41 Participating (28 Pediatric and 13 Adult) Endocrinology centers across the US. 2. Each center has between 3 – 10 active team members including Endocrinologists, Patient Representative, QI Coordinators, IT Rep, Nurses, Admin etc. 3. The Coordinating center staff including the Principal Investigators, data engineers, IT support staff, QI Coaches, data analyst and administrators. 4. Six committees including Patient/Parent Advisors, Publications, Data Governance, Data Science, Clinical Leadership.
Environment	<ol style="list-style-type: none"> 1. The centers are across 19 states in the US. 2. There are centers in urban and rural regions 3. There centers are all affiliated with academic institutions 4. The centers include both small centers (less than 500 patients), medium (501 to 1000 patients) and large centers (over 1000 patients) 5. The centers capacity and baseline culture for improvement varies widely.
Product	<ol style="list-style-type: none"> 1. Quality Improvement Portal – this is an electronic medical record online tool for center-to-center benchmarking, quality improvement case studies, centers can also generate detailed improvement reports, ranking, customizable control and run charts. 2. Largest US Real world Comprehensive database for 40,000+ patients with Type 1 Diabetes 3. 25 Peer-review publications in high impact journals 4. 60 Conference presentations at major international conferences 5. Four change packages 6. Demonstrated improvement in major processes and clinical outcomes including glycemic management.

Table 7: Mapping Exercise for Out of Hospital Cardiac Arrest Learning Community

Out of Hospital Cardiac Arrest (OHCA) Learning Community	
Goal	<p>Overarching goal: Improve survival rates for victims of out-of-hospital cardiac arrest across Washtenaw and Livingston counties</p> <p>Sub goals:</p> <ol style="list-style-type: none"> 1. Lower time to first treatment response rates 2. Raise community awareness on sudden cardiac arrest 3. Increase availability and access to public automated external defibrillators (AEDs)
Value	We want to engage all stakeholders (experts, grassroots, advocates, etc.) who are involved in the chain of survival of any out of hospital sudden cardiac arrest victim
Structure	Governed by a joint leadership structure of UM Department of Learning Health Sciences (operational arm of the Learning Community), Emergency Department and the Washtenaw-Livingston Medical Control Authority
Actor	Principal participant organizations and individuals: Emergency room cardiology and cardiac rehabilitative care clinicians from Michigan Medicine and Saint Joseph Mercy Health System, 911 dispatch and first responder agencies, Washtenaw-Livingston Medical Control Authority, SaveMiHeart, county/city/township fire departments, police agencies, sudden cardiac arrest survivors, community leaders
Environment	Academic institutions, medical systems, law enforcement and public safety agencies, non-profit and community organizations, regulatory agencies
Product	<p>Website: http://ohca.med.umich.edu</p> <p>Advertising the ongoing work of the community: Flyer: https://drive.google.com/file/d/14mHWKjRbx86vqivVnJY8nxikW-hFMP5Z/view?usp=sharing</p> <p>One-pager: https://drive.google.com/file/d/1SkLX8TG4_PwhGh9woYwhn45VXo4O-ygl/view?usp=sharing</p>

Table 1: Proposed ontology of Collaborative Learning Health Systems

GRAMMAR		VOCABULARY
Goal	what the network is trying to accomplish	* the vocabulary of _goal_ may include terms for clinical health, QI/research, psycho-social health, engagement
Value	the network's rules of engagement	* the vocabulary of _value_ may include terms for inclusivity, equality, coproduction, partnership
Structure	the network organization and relations	* the vocabulary of _structure_ may include terms for leadership, relation to healthcare environment, maturity, repository for data/digital assets (commons), hardware, how the network is funded
Actor	who/what is participating in network activity	*the vocabulary of _actor_ may include terms for people, animals, and other entities and objects that participate in the construction of relations within a network: patients, parents, advocates, healthcare providers, social workers, committees, panels, working groups
Environment	context that the network and sites are imbedded in	*the vocabulary of _environment_ may include terms for the institutional, natural, cultural, or socio-political environment that shape the possibilities for constructing relations within a network: hospital, practice, university, company, external forces, policy, funding
Product	tangible outputs of the network	* the vocabulary of _product_ may include terms for information/WINWIN, research data, innovations, network narrative (incl origin story), procedures

Table 2: Values elicited during focus group, duplicates represented in parentheses to show consonances

Co-production	Shared Learning (2)	Improving Life with those with CF
Growth	Data-based	Using QI skills
People-centered	People first	Innovation
Equality in coproduction	Generosity (2)	Achieving more together than alone
Laugh & have fun while we work	We collaborate: spirit of QI	Empathy (2)
Failure is the way we learn (2)	Contribution	Equity (3)
Shared Purpose	Collaboration	Embrace uncertainty
Transparency (3)	All teach, all learn (3)	Co-production with families
Lack of respect for the status quo	Share seamlessly and steal shamelessly	Respect for all colleagues and all ideas
Learning from Data	Respect for all	Focus on outcomes (2)
Relentless focus on outcomes	Distributed leadership	Who's at the table
Patients and families are the center of our work	We are a circle, not a hierarchy: we coproduce with our patients and families	

	Goal	Value	Structure	Actor	Environment	Product
[Network Name]						

Operational definitions:

1. Goal = what the network is trying to accomplish
2. Value = the network's rules of engagement
3. Structure = the network organization and relations
4. Actor = who/what is participating in network activity – includes inanimate objects
5. Environment = context that the network and sites are imbedded in
6. Product = tangible outputs of the network

Instructions: Please fill in the table to describe attributes of your network. You can use lists, short phrases, keywords, etc.

REFLECTION – Please take 5 minutes and write a paragraph about what it was like for you to fill this out:

Table 4: Mapping exercise for Cystic Fibrosis Learning Network

Cystic Fibrosis Learning Network	
Goal	Improve health outcomes, improve co-production, partner with Cystic Fibrosis Foundation (CFF) to innovate, co-production of care, co-production of quality improvement - Shared purpose, intrinsic motivation or build will
Value	Partnership, transparency, data-driven testing/quality improvement, quality improvement (QI) skills, equity of patient and family members, time pressure, Leaders help others to lead
Structure	Individual QI teams at CFF sites/institutions, with embedded Patient/Family Partner (PFP) on each team, with a focus of a triad (physician lead, QI lead, PFP lead); partnership with CFF. Network Leadership Team + workgroups, mentorship, snowflake model. Model for Improvement. Work is funded by CFF. Workgroups. IRB approval is already established (existing part of structure). iLabs. Strong support from operations team and Quality Improvement Consultants.
Actor	Clinicians, Patient & Family Partners (PFPs), CFF, experts and advisors, patients and families who are not PFPs, registry team, institution as entity with person-like qualities (especially for grants and permissions), members of other networks (as we learn at LNCC or through the literature and websites, we have borrowed heavily from other networks, e.g. by looking at change packages).
Environment	Institutions (care centers, etc.), honoraria and grants, COVID, time, trikafta, competing interests for time and thinking. CFLN teams are also members of Therapeutics Development Network, Success with Therapies Research Consortium, and Transplant Consortium
Product	Change packages, experienced leaders, engaged PFPs, publications, reliable clinical processes, innovations, rapid learning, build a culture of passion and curiosity, i.e. culture of improvement

Table 5: Mapping Exercise for ImproveCareNow

ImproveCareNow	
Goal	<ol style="list-style-type: none"> 1. Transforming the health, care and costs for all children and adolescents with inflammatory bowel disease (IBD) by building a sustainable collaborative chronic care network. 2. Enable/Empower patients, families, clinicians and researchers to work together in a learning health care system to accelerate innovation, discovery and the application of new knowledge 3. Achieve financial sustainability 4. Focus on health inequity, increase diversity and bridge the gap on disparities 5. Integrated Technology Platform 6. Continued focus on community engagement and patient centered outcomes
Value	Inclusivity, Honesty, Transparency, Community, Empowerment, Learning, Continuous Improvement
Structure	<ol style="list-style-type: none"> 1. Board of Directors 2. Executive Directors 3. ICN Staff 4. Anderson Center for Health System Excellence Staff 5. Community Council (represents community stakeholders with representation from each stakeholder group as listed in 6-17) 6. Physician Leadership Group (represents physician leads from selected sites) 7. Research Committee (reviews research proposals) 8. Parent Working Group (comprised of participating parents) 9. Patient Advisory Council (comprised of patients who are focused in developing patient facing tools as well as representing a patient perspective at various community fora) 10. Clinician Committee (comprised of physicians who determine and develop clinical and Qi focus for the network) 11. Data Management Committee (comprised of clinicians, parents, and patients and determine data- process, QI and outcomes measures-, tracking and reporting of these measures to the network) 12. Social Workers and Psychologist Working Group (focused on developing content and projects on mental health for the network participants) 13. Dieticians Work group 14. Coordinator Work Group-comprising of ICN/Anderson Center staff working with center coordinators for data related issues and updates 15. Nurses Work Group 16. Engagement Group (Stakeholders representative focused on improving community engagement and awareness work) 17. Regulatory Group (ICN and Anderson Center staff focused on regulatory (eg IRB) focused deliverables) 18. Diversity, Equity and Inclusion Committee(Network wide committee reporting up to the Board developing and focusing on DEI efforts for outcomes, leadership, and staffing)

<p>Actor</p>	<ol style="list-style-type: none"> 1. ICN executive leadership and staff 2. Contracted Staff including Cincinnati Children's Hospital Medical Center and others 3. Community stakeholders- physician leads, coordinators, dieticians, psychologists, nurses, parents and patients 4. Researchers including clinicians and health outcomes researchers 5. Industry partners 6. Foundations 7. Federal funding agencies (Agency for Healthcare Research & Quality, Patient-Centered Outcomes Research Institute)
<p>Environment</p>	<p>Technology Infrastructure support provided by Biomedical Informatics. Now pivoting to platform provided by HIVE Networks for Registry, Collaboration, Social Interaction, File Sharing</p>
<p>Product</p>	<ol style="list-style-type: none"> 1. Publications 2. Tools-These include patient developed and patient facing tools, Self Management Handbook, Visit planners, Growing up with IBD, Ostomy Toolkit, Shared decision making tool kit for surgery etc, etc 3. Information sharing tools like the every other week newsletter-DIGEST, LOOP Blog, CIRCLE newsletter for patients and families, etc etc 4. Quality Improvement educational modules 5. Continuing Medical Education and Maintenance of Certification credit for clinicians 6. Data and Population Management capabilities

Table 6: Mapping Exercise for T1D Exchange QI Collaborative (T1DX-QI)

T1D Exchange QI Collaborative (T1DX-QI)	
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