

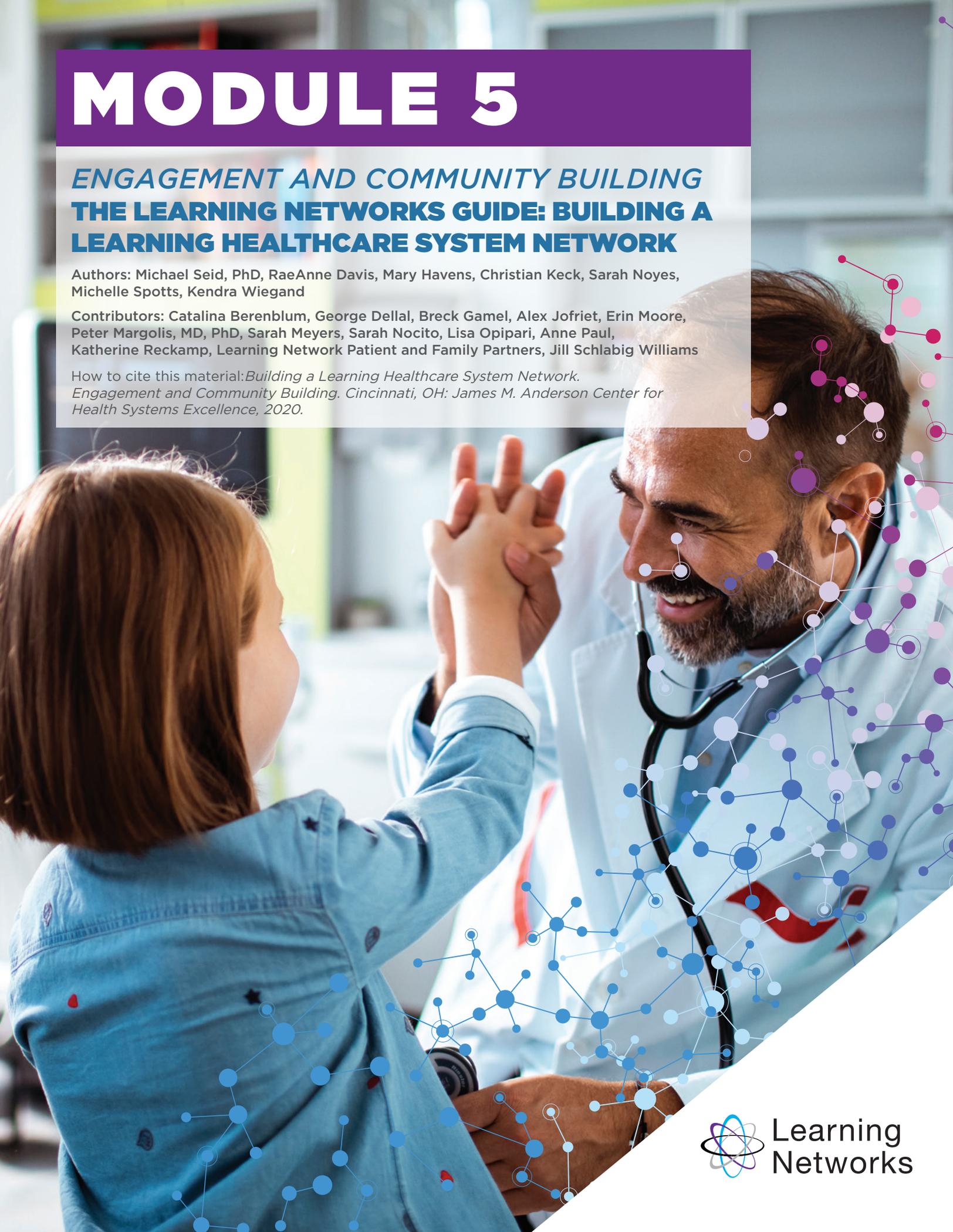
# MODULE 5

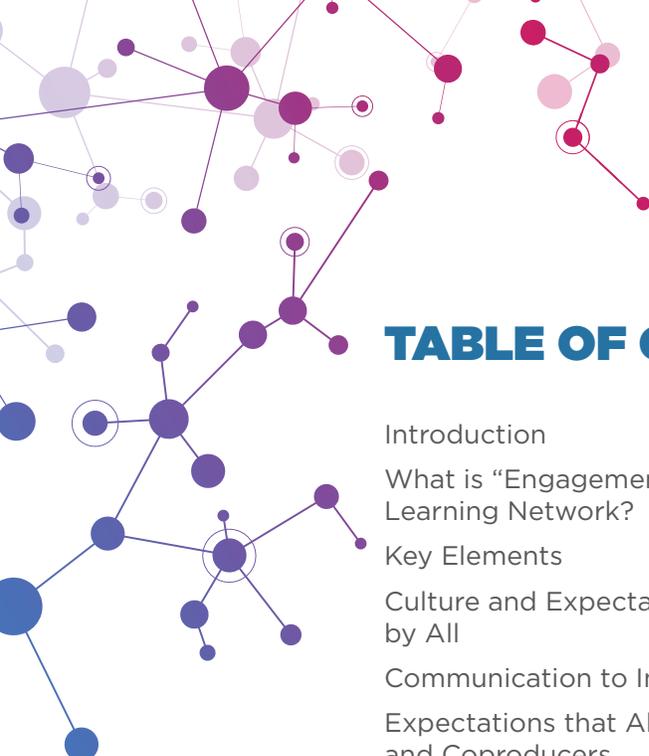
## **ENGAGEMENT AND COMMUNITY BUILDING THE LEARNING NETWORKS GUIDE: BUILDING A LEARNING HEALTHCARE SYSTEM NETWORK**

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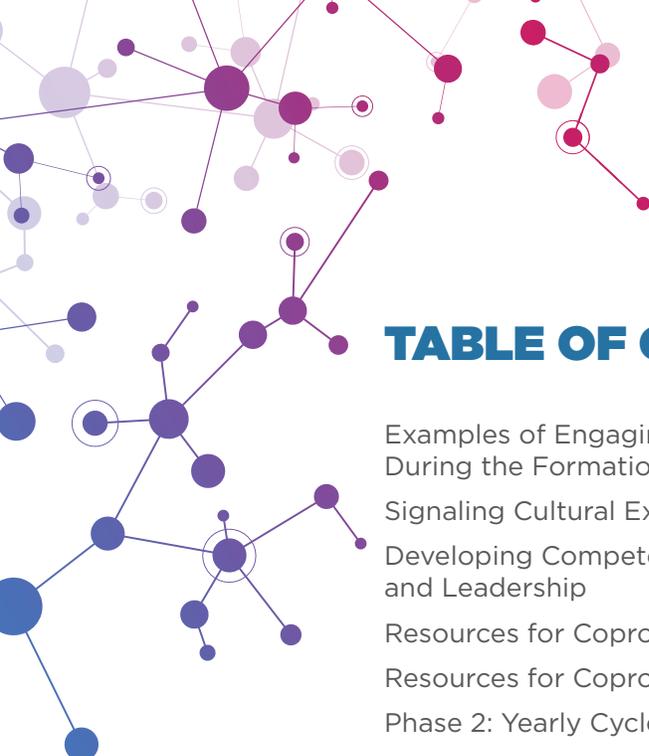




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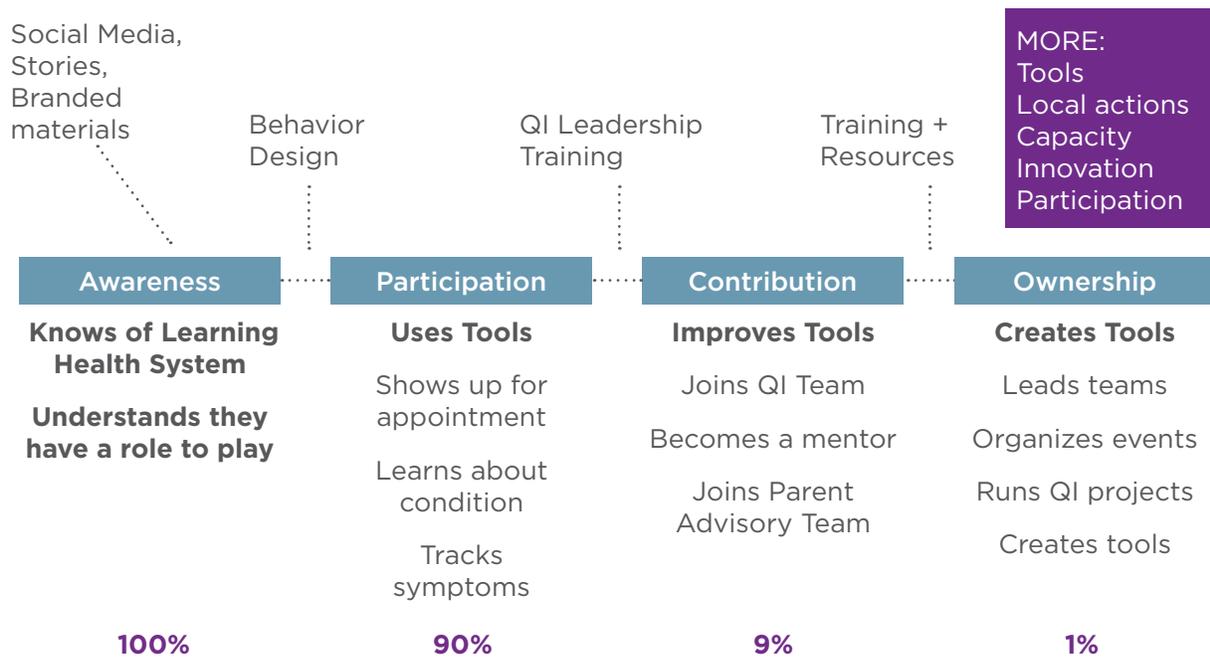
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We consider four levels of engagement (figure below). Awareness is knowing that there is a LN and what that means for one’s role in coproducing improvement. Participation is using existing tools and processes, and contribution is helping to make these tools and processes better. Ownership is taking initiative for creating new tools, knowledge, and processes. Typically, LNs begin by working with owners and contributors—people who can be highly involved and who have the capacity and capabilities to work on the system itself. This is the group that will “lay down the tracks” by creating the structures, processes, and shared resources that enable more people to become aware of and participate in the work of improvement.

A LN is a human system. It is powered by people who contribute their energies and resources to build common resources that can be used to solve shared problems. As more tracks are laid, more people can be brought into the system and participate in the work. Creating a culture and expectation of involvement by all and having a system and processes that facilitate involvement by all accelerates the work and increases the scope of the LN.



## KEY ELEMENTS

Engagement is not a separate system and set of processes from the rest of the LN; it is incorporated into all parts of it. Engagement is the end result of realizing that people have certain general and specific inherent motivations. People, by and large, are cooperative by nature (Ostrom, 1990) (Benkler, 2011) and are motivated by connection, autonomy, and mastery. (Abramson et al., 1978) (Bandura, 1982) Professionals involved in the learning network have chosen to devote their energies to improving the outcomes of interest in these networks (safety, chronic conditions, population health, etc.). Patients and parents did not choose to devote their energies to this work but they, more than anyone else, have “skin in the game.” We often think of patients who don’t take their medicine as “non-adherent.” An alternate perspective is that this represents system failure: The person with the most to gain in terms of health has been failed in their attempts to improve their health.

LNs recognize these general and specific motivations and are designed to facilitate their expression using two main strategies: creating a culture and expectation of involvement by all and having a system and processes that facilitate involvement by all (see engagement system Key Driver Diagram on next page).



# ENGAGEMENT SYSTEM KEY DRIVER DIAGRAM



## Culture and Expectation of Active Involvement by All

“A culture of involvement by all” means that learning networks deliberately develop and maintain norms, behavioral patterns, and expectations that each person and all people have valuable expertise that is essential to improving health and health care. Required elements include:

- Communication to increase awareness of the LN as well as opportunities for and the importance of being part of it
- Expectation that parents, patients, clinicians, and researchers are cocreators and coproducers
- Competency in coproduction and leadership.

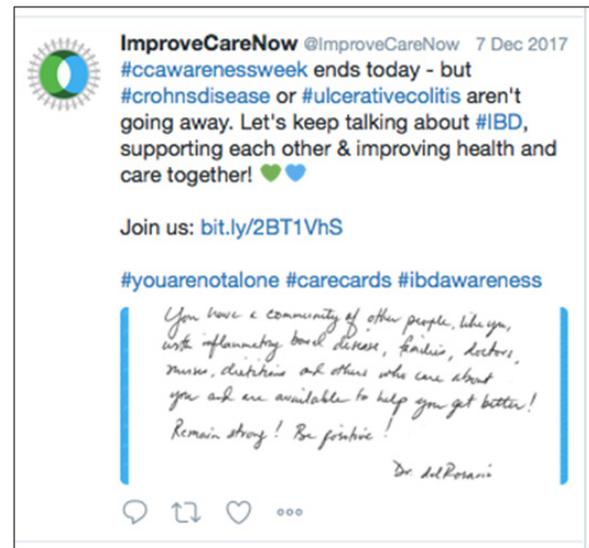


## Communication to Increase Awareness

In an ideal state of learning network maturity, a multi-channel communication plan describes strategies to engage the community and engender trust and cooperation. Content is produced by all stakeholder groups. Regular efforts, such as campaigns to increase awareness, trust, and cooperation are implemented and evaluated within strategic planning processes.

### Examples

- Healthier Together mini campaign (Appendix 5.1)
- Use of “care cards” (example to the right) in social media and at clinics
- ImproveCareNow (ICN) has an ongoing awareness campaign using a variety of social media and direct email communication, linked to peer-produced content and its website. (Appendix 5.2)
- Formal communication structure and content (communications plan): Ohio Perinatal Quality Collaborative (OPQC) communications strategy (Appendix 5.3)
- Consistent and structured messaging (including cases/stories): ICN social media mini campaign (Appendix 5.5a)
- Strategic communications structure and plan revision process: Anderson Center LN Communications Plan Template (Appendix 5.4), another example: OPQC Communications Workplan (Appendix 5.5b)



### Resources

Messaging for these awareness campaigns borrows from Marshall Ganz’s model of community organizing and uses such tools as public narrative. (Ganz, 2002) Here is a training module from ICN that teaches public narrative: [CELS Story of Self, Story of Us, Story of Now: How to talk About ImproveCareNow to Build Your Team](#)

## Expectations that All are Cocreators and Coproducers

In the ideal state of maturity of a learning network, there is a pervasive culture and expectation of collaboration and partnership. For example, ImproveCareNow’s ongoing communication campaign imparts the normative values of involvement (messages such as “You can make a difference”) and collaboration (messages such as “Let’s outsmart IBD together” and “Working with patients, not for patients”).

Time and contributions of all partners are valued, demonstrated, and celebrated. Time and contributions of patient partners are valued and acknowledged in a variety of ways including fair financial compensation, as well as reasonable and thoughtful requests for time commitments. Appropriate accommodations are made for cultural diversity and/or disability when necessary.

### Examples of Messaging

Messaging around “You Can Make a Difference” are exemplified by [LOOP](#) blog posts such as these:

- [The Strength of Our Community](#)
- [I Became My Own Worst Enemy](#)
- [To Listen](#)



## Valuing the Time and Contribution of All Stakeholders

Learning networks are powered by non-market-based production. This means, essentially, that people do things for reasons other than money (non-market). Additionally, we generally find that a small group of people make outsize contributions (e.g., the owners) and, while many owners are employed in jobs that make it possible to spend time contributing as owners (e.g., researchers, clinicians, administrators), others incur extra cost contributing at this level. For example, many patients and families must take vacation days to attend meetings or incur additional babysitting or transportation costs. As well, some patients and families are both committing extra time and using specialized skills for the benefit of the network (versus at their own care center). With money comes the danger of creating a transactional relationship (e.g., we'll pay you for this many hours per week); however, if framed in terms of recognizing time and effort (below), this danger is lessened. There are no fast rules for compensation, but this is an issue that should be addressed thoughtfully, directly, in the context of an ongoing relationship, and repeatedly.

As described by the Patient-Centered Outcomes Research Institute (PCORI) statement on financial compensation: “Fair financial compensation demonstrates that patients, caregivers, and patient/caregiver organizations’ contributions to the research, including related commitments of time and effort, are valuable and valued. Compensation demonstrates recognition of the value, worth, fairness of treatment with others involved in the research project and contributes to all members of the research team being valued as contributors to the research project.” (PCORI, 2015)

Furthermore, PCORI states, “Compensation may vary based on the nature of activities of the patient/caregivers/patient organizations who act as engaged partners and by the reach of their efforts. For example, engaged partners may be compensated on an hourly basis, by the half or full day, or by stipend. Additionally, advancement of out-of-pocket expenses may be appropriate if circumstances warrant. Compensation models should allow for some flexibility, such as allowing engaged partners to choose to decline compensation given restrictions that may apply to them (e.g., restrictions of their employers or affiliated organizations or healthcare benefits).”

### Resource

- Cystic Fibrosis Learning Network Guidance on Recognition to Patient and Family Partners (Appendix 5.6).

## Systems and Processes Support Involvement by All

“Systems and processes that support involvement by all” means that learning networks make it easy for people and institutions to create and share information, knowledge, and know-how. They have in place:

- Clinic workflows that support local engagement and partnership
- Broad participation of all constituents across all levels of leadership (local and national)
- Knowledge, tools, and ideas (a commons) that is accessible to all
- Processes, protocols, and structures that facilitate collaboration, information and knowledge sharing
- A system for continuous learning and improvement.



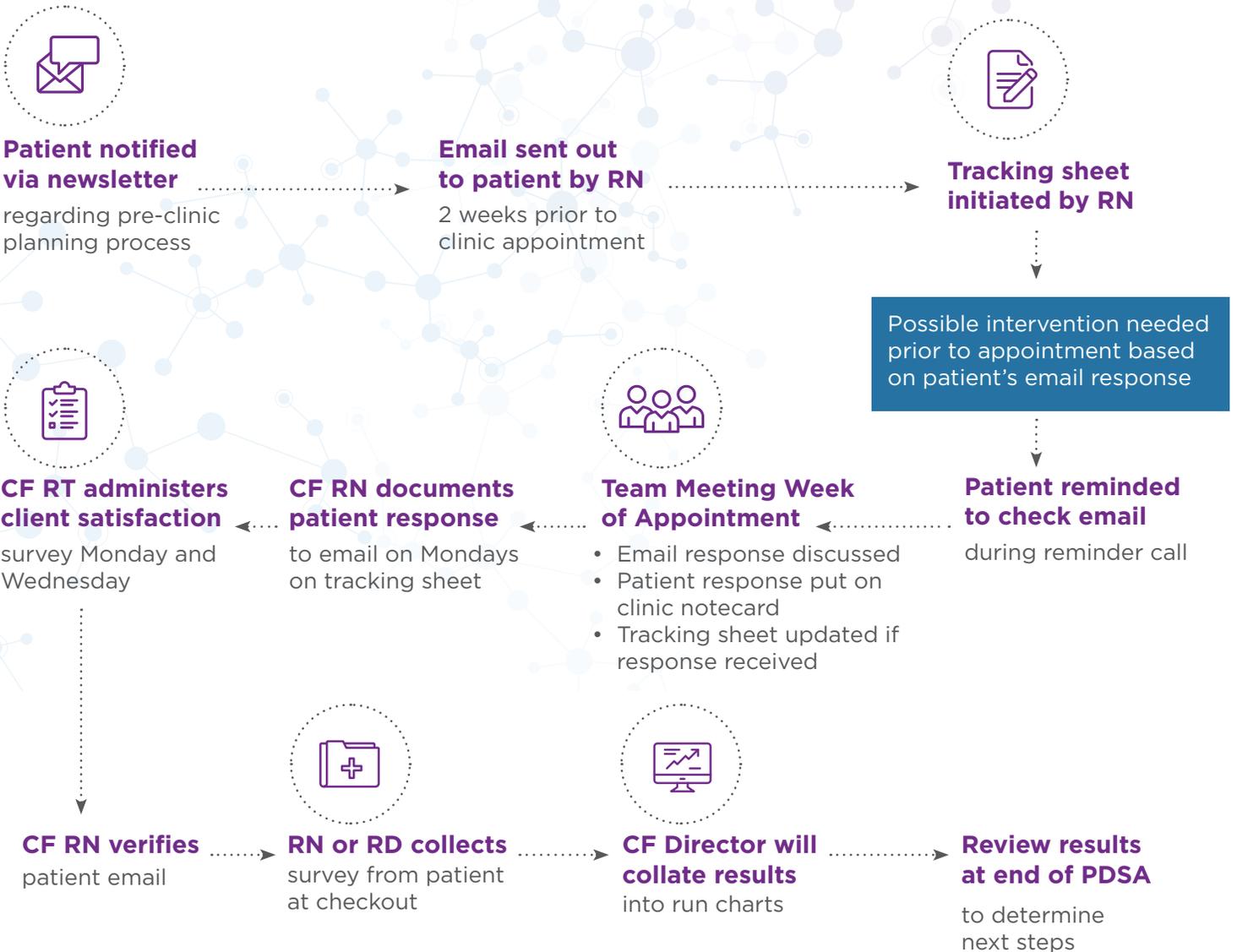
## Clinic Workflows that Support Engagement

Learning networks facilitate the coproduction of health as well as the coproduction of healthcare improvement. Clinic workflows ought to support engagement. Examples of this include processes for getting patient and parent input into pre-visit planning; tools and processes for shared goal-setting and shared decision-making; and ways to connect patients to the learning network in the context of the clinical encounter.

### Examples

- CF Learning Network Virtual Brown Bag: [Goal Setting and Goal Attainment 06 May 2016](#)
- Harvard Business Review article [“A Personalized Learning System for Improving Patient-Physician Collaboration”](#)
- Pre-clinic planning with patient involvement flow chart (see below)

## PRE-CLINIC PLANNING WITH PATIENT INVOLVEMENT EXAMPLE FROM CYSTIC FIBROSIS LEARNING NETWORK



## Broad Participation by All Constituents at All Levels

Patients and families should be incorporated into all levels of learning network governance. See Module 2: Governance and Management.

For example, ICN incorporates parents and patients at every level of the organization including the Board of Directors (five of the eight members of the Board of Directors are parents or patients).

## Knowledge and Tools Accessible by All (Knowledge Commons)

A [Learning Exchange](#) is a virtual community commons that makes it possible for a geographically dispersed community of clinicians, scientists, patients, and parents to pool their knowledge, cocreate tools, and track progress toward improvement goals intended to improve outcomes in chronic conditions. Learning networks need to create a virtual community commons where a geographically dispersed community can pool their knowledge and exchange a growing collection of tools, processes, stories, and lessons learned. The virtual community commons should function as a repository to share existing assets and as stimulus for coproduction.

## Processes, Protocols and Structures that Support Engagement & Collaboration

In an ideal state of network maturity, the vast majority (over 75%) of network partners can self-organize into functional teams and infrastructure support is available for meeting logistics and sometimes, facilitation.

### Example

- ICN Task Force Job: An example of how one of the Patient Advisory Committee (PAC) Task Forces (Recruitment) is breaking down responsibilities and defining roles. Ongoing training is being provided to Task Force leads in how to organize using 1:1's, team meetings, etc. (see in the ICN PAC Leadership Manual, Appendix 5.7)

## System for Continuous Learning and Improvement

Learning networks have a strong, shared foundation of QI (for details, see Module 4: Quality Improvement). This common approach to improvement, using common methods and language, serves as connective tissue for enabling the formation of effective teams. QI training for patients and parents facilitates the inclusion of these stakeholders on improvement teams.

Additionally, learning networks can build engagement into the learning system.

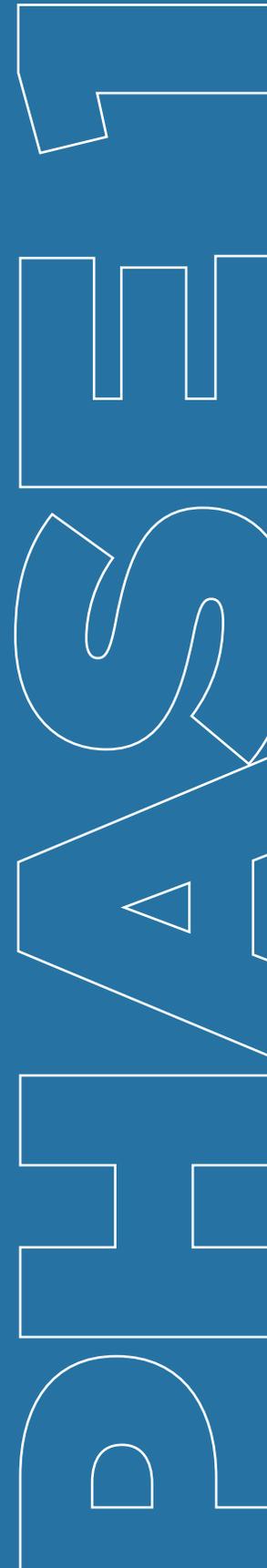
Engagement content often focuses around the care centers' efforts to identify and recruit patients and parents to improvement teams and improving the ways that these stakeholders are incorporated as full partners. Content can also be focused on making patients and parents aware of the learning network or growing the parent and patient advisory groups, either locally or at the network level. As such, learning networks can develop 90-day and annual goals focused on engagement and incorporate reporting on engagement into monthly network reporting.





# **PHASE 1:**

## **DESIGN & DEVELOPMENT**



Engagement is essential at all stages of a learning network’s life cycle. During the design and development phase, it is important to understand who stakeholders are and to include them in all processes. Doing so ensures a LN that is useful to all and builds the multi-stakeholder community that will power the LN.

Learning networks use a codesign process in which all stakeholders are represented. (Seid et al., 2018) The development of the Aim, measures, change concepts, etc. is based on collaboration among stakeholders and must be “owned” by all stakeholders. Key tasks during the design and development phase include:

- Performing a stakeholder analysis
- Forming the collaborative innovation network (COIN)
- Signaling cultural expectations
- Developing competency in coproduction and leadership.

## Performing a Stakeholder Analysis

A stakeholder analysis is a set of processes to enumerate the types or classes of people and institutions (stakeholders) who have an interest in or will be affected by the LN, and to determine their needs, objections, power, degree of support, etc. It is a way of mapping the “social landscape” of a potential LN and is useful for strategy development around building a community of participants.

### *Tips*

Typical stakeholders of a learning network include:

- Patients, family members, and caregivers
- Clinicians
- Network operations team
- Researchers and scientists
- Hospital division heads / administrators / C-level leaders
- Government agencies
- Foundations / non-profits
- Community groups
- Industry
- Insurers
- Others

Some means by which networks have collected information from their key stakeholders include:

- One-on-one conversations with a sample of stakeholders
- Surveys
- Learning Sessions
- Family Advisory Councils / Patient Advisory Councils
- Online communities
- Others

### *Resources*

- [Stakeholder Analysis Toolkit](#)



## Forming the Collaborative Innovation Network (COIN)

In the design and development phase, a small, highly motivated team of diverse individuals does the bulk of the work. While it is tempting to recruit people to this team who are similar to existing team members, intentionally diversifying the team is key to ongoing success. Stakeholder types and specific individuals revealed through the stakeholder analysis should be contacted and recruited to the COIN.

### Tips

- To get the team working well together, clear, consistent, and frequent communication among team members is necessary. Many people in academic institutions tend to share sparsely, especially if ideas or methods are partially formed. It is important to overcome this habit and to share openly and widely. Make a habit of overcommunicating, of enlarging the cc list, and of using the telephone or videoconference.
- It is also important to share work that is partially formed or “draft.” Given the complexity of system change, there is no way that any one individual can have all the answers. The only hope for forward progress is to harness the comparative expertise of a highly motivated, diverse team. Sharing complete, polished drafts slows the work because it takes longer to iterate. It also puts those responding to the draft in the “critic,” as opposed to the “playwright” mode. Sharing incomplete ideas and early drafts accelerates the cadence of iteration and learning and allows people to add their expertise early. Early sharing also builds ownership among those who have contributed.

### Resources

- [Collaborative Innovation Networks - How to Mint Your COINs](#)
- Content here: <http://www.ickn.org/collaboration.html>
- [SlideShare Collaborative Innovation Networks](#)

## Examples of Engaging Stakeholders in Leadership During the Formation of the LN

- **NPC-QIC and Sisters by Heart:** Sharing Leadership - Sisters by Heart is a volunteer organization that strives to help moms with newly diagnosed Hypoplastic Left Heart Syndrome (HLHS) babies. All volunteers are moms with children who have HLHS and who understand challenges newly diagnosed families are facing. Sisters by Heart partnered with the National Pediatric Cardiology Quality Improvement Collaborative ([NPC-QIC](#)) to decrease mortality and improve quality of life for infants with single ventricle congenital heart disease and their families. Board Members of Sisters by Heart also serve as Parent Leads, Transparency Workgroup Co-Leads, and Mortality Workgroup Members with NPC-QIC.
- **SPS:** Engaging Senior Leaders - Executive leadership is a critical aspect of successful improvement in pediatric patient safety. The Solutions for Patient Safety network ([SPS](#)) has designed efforts to inspire and continuously develop the safety leadership skills of the executives who lead its network hospitals. More than 400 hospital leaders attended the September 2017 SPS National Learning Session for leaders. The SPS network is built on the fundamental belief that by sharing successes and failures transparently and learning from one another, children’s hospitals can achieve their goals more effectively and quickly than working alone.
- **OPQC:** Engaging Senior Leaders - Many of the strategies your team tests will depend on making changes in practice, culture and infrastructure. Such changes usually require the input of a variety of individuals to adapt and implement changes in your setting. Ohio Perinatal Quality Collaborative ([OPQC](#)) engaged senior leadership in their improvement team. Such support helped remove implementation barriers and assure the long-term adoption of new strategies.



## Signaling Cultural Expectations

Learning networks are powered by the work of individuals who make contributions for a variety of motivations, including but not limited to altruism, feelings of connection, mastery, idealism, and reputation enhancement. Benkler and others (Benkler, 2006) call this “non-market-based production” and it is seen in many web 2.0 sites like Wikipedia, TripAdvisor and Yelp; citizen-scientist endeavors such as the National Audubon Society’s Christmas Bird Count, Foldit, and SETI@home; and elsewhere. While transactional relationships (e.g., paying people to participate or to perform certain tasks) are not incompatible with non-market-based production, it thrives best when contributions are driven by inherent motivations. A strong culture—emphasizing, for example, generosity, openness, and sharing—can accelerate contribution to and development of the LN, such a culture is essential to the success of a LN.

“Signaling” is the term social scientists use for how people show what norms and behaviors are appropriate and inappropriate in a culture. Signals could be artefacts such as written documents. They could be behaviors, such as approbation or censure. What items are on meeting agendas, who is held up as an example, and which problems are a focus are also signals of culture.

### Examples

- Beginning a design meeting or community conference with a “charge” from a patient or family member.
- Creating and reviewing “ground rules” for how we treat one another, values we hold in common.
- Highlighting care centers that have made positive changes in process or outcome measures.
- Drafting mission, vision, and value statements.
- Name tags at design meetings that denote patients and families as “expert” (e.g., Polly Patient, Expert), and other people (e.g., clinicians, researchers) with their professional role (e.g., Carole Clinician, Pulmonologist).
- Keeping participants’ faces visible during videoconference meetings
- Having a standing agenda item at every meeting to review the data dashboard.

## Developing Competency in Coproduction and Leadership

In an ideal state of learning network maturity, there exists a robust, distributed training system for coproduction. Leaders are systematically developed at the local and network levels by progressing along a well-described and documented ladder of engagement. All network stakeholders at the individual and network levels should understand and be competent in coproduction. There is a sparse but growing literature on patients’ experiences partnering with clinical teams for improvement, which suggests both benefits and challenges. See, for example, the exploration of patient inputs and challenges in a quality improvement project by Pomey and colleagues. (Pomey et al., 2015)





## Resources for Coproduction Training for QI

- ICN’s coproduction training in ICN Coproduction Change Package (Appendix 5.8)
- ICN Welcome Packet (Appendix 5.9): informational brochure that the [Patient Advisory Council](#) used to send out to prospective members when they were thinking about joining the group.
- PAC orientations are held once a month for prospective members who have signed up online. Meetings are typically held for one hour in the evenings, led by PAC Recruitment Task Force leads, and supported by the ICN Engagement Coordinator. (Orientation Call slide deck: Appendix 5.10)

## Resources for Coproduction Training for Research

- ICN coproduction training (referenced above, Change Package [Appendix 5.8] or ICN Building Coproduction into the Woodwork [Appendix 5.11])
- ICN Research Coproduction guide (Appendix 5.12)



# PHASE 2: YEARLY CYCLES

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## Examples and Resources

- CFLN has a coproduction readiness assessment to be completed by both potential PFP and the clinical site coproduction clinician (Appendix 5.13)
- Pediatric Rheumatology Care & Outcomes Improvement Network (PR-COIN) models for engagement at the local and network level (“Models of parent & patient engagement”: Appendix 5.14)
- PR-COIN “Engagement brochure” (Appendix 5.15): prepared by the Parent Working Group (PWG) to outline ways to engage parents and patients at their local sites and within the greater PR-COIN network
- PR-COIN “PWG letter to prospective sites” (Appendix 5.16): a letter that PR-COIN parents send to new centers who join to encourage them to look for a parent
- Patient Engagement interview guide: for a collaborative interview with a new parent advisor (Appendix 5.17)
- Formal network roles for patient / family partners: CF family partner roles (Appendix 5.18) and CF family partner job description (Appendix 5.19)
- ICN role descriptions for communications, recruitment and advocacy task forces are in the ICN Welcome Packet (Appendix 5.9)
- Formal method to identify and fulfill collaboration opportunities: PAC Project Selection and Development process map (Appendix 5.20)
- Welcoming a new parent with PR-COIN “PWG introduction given to potential members nominated by teams”: document created by PR-COIN parent group when welcoming a new parent to their group (Appendix 5.21)
- ICN asks about interests when recruiting & onboarding for the PAC – see PAC onboarding process map (Appendix 5.22)

## Develop QI Competence for Patients and Families

QI is the process by which LNs improve. It is also a shared framework and shorthand for how LNs solve problems together. While advanced QI training is available and important, having a basic understanding of the QI framework and terms is foundational to coproduction.

### Resources

- The Community Innovators team in the CF Learning Network made a series of brief videos introducing QI to patients and families:
  - Introduction: <https://vimeo.com/266496842>
  - Setting aims: <https://vimeo.com/266495374>
  - Designing Measures: <https://vimeo.com/266495363>
  - Process Mapping: <https://vimeo.com/266495361>
  - Run charts: <https://vimeo.com/266495340>
  - PDSA Cycles: <https://vimeo.com/266495325>
  - PDSA Ramps: <https://vimeo.com/266495286>
- All Children Thrive developed a form for coaching parent leaders. It allows staff to understand how parent leaders feel about the work they are doing and look at ways to try out (test) new ideas: Example Coaching form (Appendix 5.23)



## Establish Paths for Patients/Families to Contribute

There are a variety of different roles and structures available at the local and network level. Making people aware of these opportunities is useful. It is helpful to have a process for turning ideas into action. The ICN PAC (example below) has developed a map showing the flow of activities from new idea to complete toolkit.

### Examples

- An example of making people aware of opportunities to engage is the PR-COIN Model for Engagement (Appendix 5.14)
- ICN PAC Project selection and development process map (Appendix 5.20)

Multiple examples of successful coproduction are available network-wide

- [ICN tools](#) developed with patients and parents
- [NPC-QIC tools](#) developed by patients and parents in collaboration with mental health professionals

## Systematize Coproduction of QI at the Program Level

There will be substantial variation across care centers in the degree to which PFPs and clinicians are able to coproduce QI at the program level. Systematizing this process and sharing the work of improving coproduction will accelerate the rate of improvement across the network.

### Resources

- The CFLN has chartered (Appendix 5.24) a PFP program using this KDD (Appendix 5.25), surveys PFPs monthly regarding their level of engagement in the work of improvement using this scale (Appendix 5.26) and has ongoing PDSAs (Appendix 5.27).

## Energize the Network by Systematically Increasing the Number of People Involved at All Levels of Engagement

Once the “tracks” are laid, it is time to invite more people to be part of the work of the LN. This is done through awareness campaigns, growing local leadership through organizing and training, and making it easier for people to “get what I need when I need it.” Further development and support of network-level patient and family teams such as the “Patient Advisory Council” (PAC) or “Parent Working Group” (PWG) is important here as well.

### Raising Awareness

In addition to the broadcast and social media awareness campaigns described in the section “Communication to Increase Awareness,” above in this module, LNs increase awareness via virtual brown bags (VBBs) and virtual community conferences (VCCs) as well as through direct outreach by clinicians to patients and families in clinics. LN websites serve as awareness raising tools and offer opportunities to get involved in a variety of ways.

### Examples

- [ICN Virtual Community Conference Videos](#)
- [ICN Join our CIRCLE](#) offers different ways to get involved whether a parent, patient, researcher or healthcare professional
- [ICN Research Opportunities page](#) is a hub for researchers to sign up for emails, connect with patients/parents, submit a proposal, etc.
- [ICN Events page](#) has national events, local events, research & volunteer opportunities



## Growing Local Leadership – Organizing Training

Just as the LN is energized at the network level by having more people more involved, so too is local care center work energized by more involvement. In fact, accelerating coproduction of improvement and innovations at the local level is a powerful way to accelerate change. If local teams can identify, recruit, and organize volunteers, they will be able to increase their capacity and capabilities. LNs borrow techniques and practices from community organizing to increase the local teams' abilities to grow new leaders.

### Resources

- [Organizing: People, power, and change](#), an organizer's handbook, is a good resource for more about community organizing
- ImproveCareNow uses a series of webinars to teach basic community organizing practices to parents, patients, and clinicians at ICN Centers to help them organize themselves at the local level. These are designed to increase participation, contribution, and ownership at the care center level. All four are here: [https://www.improvecarenow.org/community\\_engagement\\_learning\\_series\\_videos](https://www.improvecarenow.org/community_engagement_learning_series_videos).

Individual YouTube links:

- o Volunteer Recruitment: [July 2018 Community Wide Webinar](#)
- o Relationship Building: [CELS Relationship Building to Support Team Development](#)
- o Team Model: [CELS: How to Build an Engagement Team \(Part 1\): Snowflake Model & Team Roles](#)
- o Personal Story: [CELS Story of Self, Story of Us, Story of Now: How to talk About ImproveCareNow to Build Your Team](#)

### Tips

- “Grow a list and use it”—this is the basic mantra behind community organizing. You need to have a list of people, build relationships with and among them, and develop leaders who will take on tasks.
- Local versus LN work—There can be a perception of competition between work done by patient or parent groups at the local level and work done for the LN. This is a competition over the time and attention of busy families who may or may not volunteer. It will be important to establish working relationships with the local patient or parent groups and find out how to be helpful to them. Community organizing is not about taking volunteers away from the local work or supplanting the local group in importance. It is about helping the local groups become more effective at organizing so that they can take on more work to improve outcomes.
- HIPAA and Privacy—Campaign-focused political organizing relies on voter information, which is publicly available. Clearly, information about who is a patient and their private health information is not. It is important to understand HIPAA rules about what PHI and what organizations are “covered entities.” It is often more effective to enlist clinicians to make their patients aware.

## What I Need When It's Needed

Engagement does not occur for its own sake. The point is not to have more people involved. The point is to make it easier and more likely for people to be able to connect to the information, knowledge, know-how, or other people that they need when they need it. Once tools and resources are available, it is necessary to create ways for these to flow to the people who need them. The more information a LN has about a patient or family, the better it might be at connecting them with what they need when they need it.

## Supporting Patient Advisory Councils and Parent Working Groups

LNs have developed processes and resourcing to support the work of PACs and PWGs. See resources under the section “Identify and Onboard Patient/Family Partners at Local Care Centers” in this module.





# **PHASE 3: SUSTAINING THE NETWORK**

If designed and piloted correctly, an engaged community will be the power behind the maintenance of the learning network.

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