

Learning Health Systems Can Link People, Information, and Knowledge to Create Better Health



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Learning Health Systems for Coproducing Health, Value, and Science

Background, Aim

In 2013, a group of patients, clinicians, and researchers developed a conceptual model, where **data collected at the point-of-care can be re-used for multiple purposes**, with the aims of:

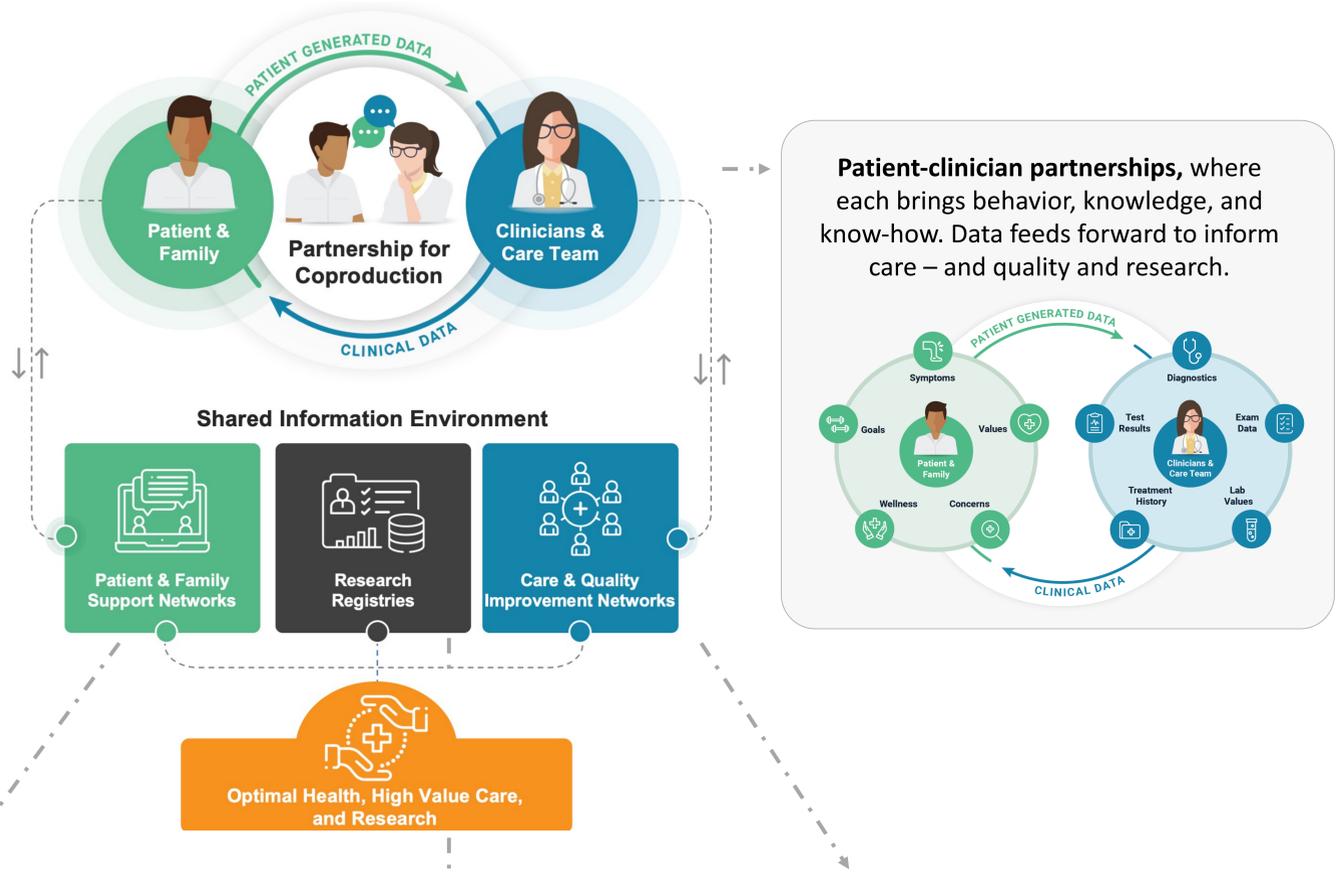
- Creating optimal health and high value care
- Supporting improvement, science, & continuous learning

Actions Taken

- Co-design functions, forms, and workflows that support coproduction of healthcare services
- Identify key PROMs and clinical data
- Enable designs with technology partners
- Implement and test in real-world clinics

100+ Co-design members	62 Clinic teams	5 Patient advocacy organizations	7 Technology partners
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Health conditions: Cystic fibrosis, Inflammatory bowel disease, Rheumatology, Multiple sclerosis, Palliative care & serious illness



Patient & family support networks to share information and expertise of real-life experiences and to provide support.

Research registries to analyze data across sites and learn what interventions work best for which patients under what conditions.

Care and quality improvement networks to share expertise and experience among health professionals to improve outcomes.

Tips for Getting Started

- **Leadership team:** Meet regularly with small dedicated team
- **Metrics of success:** Identify desired outcomes
- **Co-design team:** Meet regularly with a team of patients, families, community members, clinicians, and researchers
- **Human-centered design:** Develop and prioritize functions, forms, and workflows that support use of new tools
- **Technology partners:** Work in real-time to develop and test tools
- **Formative evaluation:** Understand feasibility, utility, and value
- **Integrate IT systems:** Feed data forward for better health, care, and research

"We often forget to ask certain questions, and the dashboard reminds us to focus on the patient's concerns rather than just looking at a clinical picture." – **Rheumatologist**

"The biggest value of the dashboard is that we actually have prospective patient identified data that can help us go forward and feed the population management tool and really give us an idea of how a patient is doing over time." – **Gastroenterologist**

"My role is to represent the patient side of things. Because the doctors and the team can talk all about it, but they don't live it. ... what I'm seeing as a patient can be very different than how the doctor uses it and what they see." – **Co-design member; Parent of a child with CF**

What We've Found

- Patients and clinicians can work together to co-design tools and workflows that support coproduction of healthcare services.
- Developing tools that meet the needs of patients and clinicians requires cooperation.
- Technology systems that are integrated within standard workflows have the greatest chance for success.