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SPEAKER ABSTRACTS

A Collaborative Chronic Care Network (C3N) is a Peer Produced Learning Health System

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Award: Transformative Research Award

Awardee Institution: Cincinnati Children's Hospital Medical Center

What if we could create a vastly better chronic care system by harnessing the inherent motivation and collective intelligence of patients, clinicians and researchers? What if this system allowed patients, physicians and researchers to share information, collaborate to solve problems, and learn from every clinical encounter so that this knowledge could be applied at the point of care? Over the last 5 years, we used commons-based peer production to design and develop such a peer-produced learning health system - a Collaborative Chronic Care Network (C3N). We worked with a network of care centers for children and youth with Crohn's disease and Ulcerative Colitis (the ImproveCareNow Network) to improve outcomes, transform health care delivery, spawn innovation, and increase the capacity for research.

A C3N is not an intervention – it is a platform for creating and testing interventions. We have demonstrated:

- Ongoing outcomes improvement. Since 2007, the proportion of patients in remission (inactive disease) increased from 59% to 79% without new medications.
- Exponential growth in the number of care centers (from 19 to 71) a registry of >19,500 patients (~40% of children in the country with the condition).
- A robust community of over 100 innovators contributing to the model
- Partnership with patients and families collaborating with one another and with other stakeholders in all aspects of the system (governance, improvement, research).
- A “data-in-once” informatics architecture enabling data to be easily captured during clinical care and re-purposed for care planning, quality improvement, and comparative effectiveness research.
- Capacity to use registry data to conduct simulated trials replicating studies not possible in children, because of time, cost, and ethical concerns (withholding an efficacious treatment) demonstrating a comparative benefit of anti-TNF α versus placebo and thiopurines.
- Novel use of mobile health technology to enable individuals to collaborate with their clinicians to track symptoms and use those data to guide shared clinical decision-making.
- A pipeline of innovations and a design and development process to manage innovation development.
- Policies that promote data sharing and regulatory approaches (e.g., common IRB) to reduce the “transactional” costs of participating while maintaining patient privacy and ethics.

Results to date suggest that this model of a peer produced learning health system has significant potential to transform care delivery, reduce the cost of research by creating a reusable infrastructure, and accelerate the speed at which new knowledge is implemented.