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Case study

www.source4networks.org.ukEmail: england.si-networks@nhs.net

Learning from Networks case study

Tackling chronic disease through an international, collaborative network

George Dellal

Background

As part of a series profiling networks across the world, this Learning from Networks case study describes the journey of ImproveCareNow and the learning that network leaders can take from its experiences.

These stories are being developed by NHS England and NHS Improvement's [Sustainable Improvement team](#) based on the experiences of a rich mix of system leaders from a wide range of sectors all committed to, and involved in, improving health and care services.

The ImproveCareNow Network

ImproveCareNow is a global network of clinicians, medical centres, patients, families, researchers and improvers working together to improve the lives of children with Inflammatory Bowel Disease (IBD). IBD is a group of chronic conditions (including Crohn's disease and ulcerative colitis) that cause pain, inflammation, frequent diarrhoea, weight loss and delayed growth.

Here, George Dellal, Quality Improvement Coach for ImproveCareNow and Senior Consultant with Kaleidoscope Health and

Care, describes the network's experiences and how it has driven improvements in care for children with IBD.

Why was ImproveCareNow set up and what does it aim to achieve?

ImproveCareNow was established in 2007. At that time, there were very limited clinical guidelines for IBD, and there was significant variation in the care and treatment that children across the US were receiving. The network was set up to bring care centres together, reduce variation and improve reliability of care, and improve outcomes for children. We describe our purpose as "to transform the health, care and costs for all children and adolescents with Crohn's disease and ulcerative colitis (also known as Inflammatory Bowel Disease or IBD)".

The network started with nine care centres, with funding from the American Board of Pediatrics, but grew significantly in 2009 when we partnered with researchers interested in developing an innovative model for chronic care called the Collaborative Chronic Care Network (C3N), housed at the Cincinnati Children's Hospital Medical Center.



This was a new initiative using patient data to drive improvements and encouraging collaboration between patients, caregivers, clinicians and researchers.

Who is currently involved in the network?

The network is now made up of 109 care centres in 39 states, as well as England, Qatar and Belgium. It involves multi-disciplinary teams including clinicians, dieticians, psychologists, social workers, nurses, and a lively patient and caregiver community. A board of directors and strategy council oversee our work.

How does your network include patient, carers and service users?

Patients and caregivers are well represented on our board, where they help to guide all of our activities. In addition to this, we actively use what we call the Ladder of Engagement, which lays out how we engage patients and caregivers at four different levels: awareness (e.g. via newsletters, social media); participation (e.g. attending webinars, using resources); contribution (e.g. writing a blog, taking part in QI activities) and ownership (e.g. leading and suggesting ideas).

How do your network members connect with each other?

We have an online platform called the ImproveCareNow Exchange, where network members can share and actively develop resources, tools and ideas. We also have monthly calls between members, and twice yearly we have face-to-face community conferences, where we meet to work on developing and spreading QI and research skills and approaches, and to develop new partnerships with each other. Patients and caregivers also connect with each other through our thriving Patient Advisory Council and Parent Working Group, respectively.

In the past year, what has been the most significant thing you have learnt with regards to the role and value that networks can play in supporting quality improvement?

“Our Pathway to Mastery project has been fantastically valuable for patients and caregivers.”

In my view our most significant learning relates to our Pathway to Mastery project, which aims to reduce variations in remission rates across the network. In 2011 we received a \$12m government grant to develop a data and analytic infrastructure, which enables us to track and analyse data on care centre IBD processes and outcomes. Using these data we have been able to divide centres up into three groups based on their remission rates – those that had rates at 82% or above, which we support in their efforts to sustain remission; those trying to get to 82%, which we work with to increase their reliability of chronic care processes; and those we call ‘foundations’, which are trying to gain regulatory approval and get > 75% of their IBD population registered in the database.

This has been a fantastically valuable project and we found that many centres are enthusiastic about getting involved by co-designing interventions. On the more challenging side, we’ve found that there is significant variation in how centres define ‘sustained remission’, which creates obvious difficulties when ascertaining data quality. As a result, we’ve chartered a group of network members to refine our operational definition of ‘remission’.

What tools and resources have you made use of in your network?

We make use of vast amounts of data from our database in real-time. In addition, each of our three pathways has a driver diagram and a theory of change to help maintain clarity on its objectives and how to achieve them.

We use our monthly calls to clarify and reinforce our expectations of each of our care centres.

What has your network achieved?

We've seen some fantastic improvements in care and outcomes for children and adolescents with IBD since the network was established. These have included:

- 30,000 children and adolescents have been treated as part of the network
- 94% have satisfactory growth
- 82% are in remission
- 55% have sustained remission for at least one year
- 90% show satisfactory nutrition
- 97% are not taking steroids.

What are the key messages that you would like to share in relation to this work?

There are four key ingredients that I believe have contributed to the success of the network:

- Developing and staying focussed on a clearly defined purpose
- Approaching data and measures rigorously and transparently
- Using a common pool of resources (sharing seamlessly, and stealing shamelessly)
- Systematically engaging with the community.

Contact

If you would like more information on the ImproveCareNow network, please contact George Dellal at george@kscopehealth.org.uk.

Further reading

ImproveCareNow website - www.improvecarenow.org

Fagotto, E. (2019) - Exchanging Information to Create a Learning Health System: The ImproveCareNow Approach to Engagement.

Project on Transparency and Technology for Better Health, Harvard Kennedy School Ash Center.

Source4Networks

www.source4networks.org.uk – provides a platform for network leaders and those leading, or aspiring to lead, networks to connect with each other and benefit from each other's experience in order to strengthen the effectiveness and impact of their networks, and to spread innovation and good practice.