Learning to make a difference for chILD: Value creation through network collaboration and team science

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Abstract

Addressing the recognised challenges and inequalities in providing high quality health care for rare diseases such as children's interstitial lung disease (chILD) requires collaboration across institutional, geographical, discipline, and system boundaries. The Children's Interstitial Lung Disease Respiratory Network of Australia and New Zealand (chILDRANZ) is an example of a clinical network that brings together multidisciplinary health professionals for collaboration, peer learning, and advocacy with the goal of improving the diagnosis and management of this group of rare and ultra-rare conditions. This narrative review explores the multifaceted benefits arising from social learning spaces within rare disease clinical networks by applying the Value Creation Framework. The operation of the chILDRANZ network is used as an example across the framework to highlight how value is generated, realised, and transferred within such collaborative clinical and research networks. The community of clinical practice formed in the chILDRANZ multidisciplinary clinical peer support meetings provides a strong example of social learning that engages with the uncertainty inherent in rare disease diagnosis and management and pays attention to generate new knowledge and best practice to make a difference for children and families living with chILD. This review underscores international calls for further investment in, and support of, collaborative expert clinical networks for rare disease.
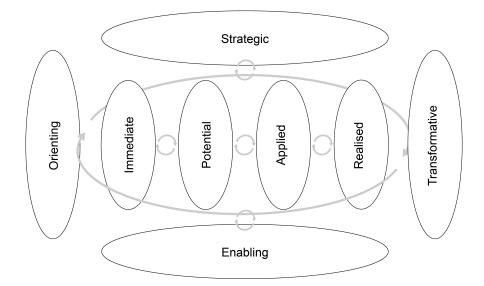
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Strategic

Orienting

Immediate

Potential

Applied

Realised

Transformative

Enabling

Strategic value
The clinical network aligns with patient advocacy groups, engaging with them to frame network priorities and principles. The network interacts with other national and international networks to collectively shape strategic directions.

Orienting value
A diverse group of multidisciplinary health professionals bring their varied perspectives and expertise to an inter-organisational network, which is part of an ecosystem of interconnected clinical networks.

Immediate value
Participants enjoy the connection and sharing cases and experiences. They receive feedback on their professional practice in a supportive collegial environment. Patients take comfort knowing their case is being considered by an expert group.

Potential value
Engagement develops knowledge, expertise, and confidence. Participants receive advice and ideas for their current cases. They form connections and broaden their professional network. Participants collaboratively develop resources, tools, and protocols.

Applied value
Participants apply their new knowledge and expertise to their professional practice. Their clinical decision-making reflects the best practice approaches that have been generated in the social learning space. Resources are used by others.

Realised value
Accurate diagnoses and innovative treatment plans result in best possible health outcomes. Increased confidence and professionalism results in improved patient experience outcomes. Reduced isolation and increased clinician wellbeing. Experiences shared back to group.

Transformative value
Lasting changes in participants' attitudes towards teaching, learning, and quality improvement. Other groups recognise the value of the model and replicate it. Clinicians are empowered to engage with, and advocate for, the patient community.

Enabling value
Regular, accessible meetings are enabled through videoconferencing technology. Effective communication by clinicians who donate their time to act as facilitators. Decision-making is shared in a disseminated leadership model.