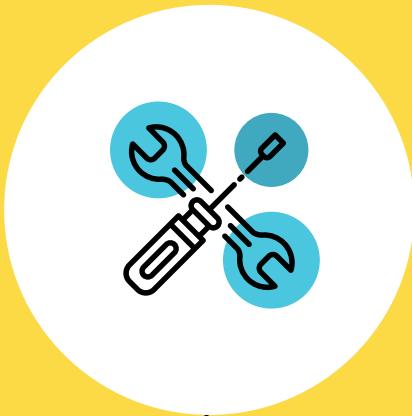


FRAMEWORK PILLAR: Equipping Providers
CASE STUDY: The Global Nursing Network for Rare Diseases



A community of practice for nurses from around the world to learn about rare diseases through knowledge exchange and resource sharing.

Context

Nurses make up approximately half the global healthcare workforce. They are often the first, if not the only, healthcare professional whom patients encounter—making them an essential resource when searching for a diagnosis.

Nevertheless, nurses are not always actively involved in efforts to accelerate diagnosis for people living with a rare disease. For example, educational resources for nurses tend to focus narrowly on disease presentation, diagnostic pathways for specific rare diseases, or specialized areas (such as genomics), rather than support nurses to develop broader expertise in the complex rare disease field.



The Global Nursing Network for Rare Diseases

Overview of program

The Global Nursing Network for Rare Diseases (GNNRD), established in 2023, is an effort to consolidate resources on rare diseases and tailor them for nurses, better equipping them to diagnose and care for people living with a rare disease.

The brainchild of the Clinical Centre of Expertise for Rare and Undiagnosed Diseases at Perth Children's Hospital (Rare Care Centre) in Australia, the Network is creating a global community to facilitate cross-learning about rare diseases and educate nurses on rare disease symptomology. The Network aims to shorten the time to diagnosis and provide better care for children and adults throughout the patient journey.

In developing the Network, the team explored models of care for people living with a rare disease and the role of nurses, and benchmarked essential elements across the patient journey—including screening, care coordination, psychosocial support, ongoing management, and access to clinical trials and treatment.

These elements underpinned a framework introduced at the "Nursing Roundtable," held in Singapore in March 2023. The event, co-hosted by the Rare Care Centre, SingHealth Duke-NUS Genomic Medicine Centre (an academic medical center), and Curtin Singapore (a public research university), included people living with a rare disease, their families, and 33 nurses from 25 countries across various regions. The input the Centre received laid the foundation for the GNNRD, establishing a community of practice that strives to be equitable and scalable.

Global Nursing Network's objectives include:



Connect and increase global collaboration among nurses working with people affected by rare or undiagnosed diseases.

Provide nurses with resources to promote and implement comprehensive care for people living with rare or undiagnosed diseases.



Inform and influence the development of nursing education resources to upskill and raise awareness of rare and undiagnosed diseases across the nursing workforce.

Strategically influence local, national, global policy and advocacy platforms by bringing nurses to the table of high-level organizations to advocate for people living with rare and undiagnosed diseases.



Guide nurses in assisting families to navigate the clinical trial space.

Connect and share expertise with other regional and disease-specific networks.



The Network is virtual, and nurses are connected through a website, enabling them as well as nursing students to access educational resources (e.g., webinars, learning modules, rare disease country recommendations), opportunities to collaborate on projects, a forum to discuss questions about cases, and information about travel scholarships to attend conferences or workshops related to rare disease.

Results

Now at its one-year mark, the Network's members include 280 nurses from almost 40 countries, more than half of which are low or middle-income.⁹ Momentum is growing rapidly, with interest in establishing both regional and national versions of the Network, such as an Asia-Pacific chapter and a Brazil chapter.

While the Network is in its infancy, it has already had a notable impact in various countries around the world:

- The Dean of the Faculty of Nursing at the University of Colombo, Sri Lanka, who is a Network member, included a genetics module in the Nursing Bachelor of Science program offered by the University. With 100 nursing students starting the degree each year, adding this content to the curriculum will significantly augment future nurses' knowledge of rare and undiagnosed diseases.
- The Network connected the Universitas Gadjah Mada Academic Hospital in Indonesia with the National Taiwan University Hospital to undertake a benchmarking exercise to support Indonesia's newly developed clinical genetics service. A member of the GNNRD also contributed technical expertise to help establish the Indonesian hospital's genetics program and biobank, which will support the government's Biomedical & Genome Science Initiative to enhance precision medicine in the country.
- Thanks to a Network member, the GNNRD has been included in the refreshed Wales Rare Disease Action Plan (2022-2026) as a partner to develop education and training for nurses, building their knowledge and capacity related to rare and undiagnosed diseases.

In addition, the Network has partnered with Medics4Rare (a charitable organization that creates resources to educate doctors and medical students about rare disease) to develop e-learning modules specifically for nurses and nursing students, helping them identify the signs of rare diseases in children.

The Network is also planning to create resources for teachers, such as animated videos, to help guide conversations with children who have a rare disease and their families. The goal is to make these materials culturally relevant and translate them into multiple languages so they can be used across a variety of regions.

Learnings

The success of the Global Nursing Network for Rare Disease, although in its early days, underscores the power of global collaboration and the value of partnerships, co-creating solutions, and creativity in testing new ways to engage health professionals to deepen knowledge of rare disease.

- **Partnerships are critical to establishing credibility:** A key part of forming the Network was leveraging relationships with global rare disease leaders who contributed their expertise—providing credibility, which was essential to secure financial support—and promoted the Network through their channels.

- **Co-design with target audience:** The Rare Care Centre was intentional and methodical about collaborating closely with nurses to design the GNNRD. For example, the Centre organized a series of meetings and workshops to gather nurses' input and gain buy-in for this project—well before launch. The nurses involved were asked to validate findings from the workshops to ensure that the Centre accurately captured their needs, highlighted the most significant accomplishments to funders, and outlined agreed-upon milestones for the upcoming year.

In addition, the Network partnered with academic institutes to build connections with nursing education specialists and advise on the best platforms and content to use when developing educational resources for nurses. Likewise, teachers will be brought in for a workshop to help craft the animated video to ensure it reflects their needs across the globe, spanning cultural and linguistic diversity.

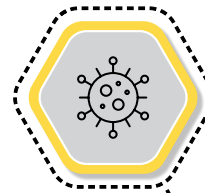
- **Creative formats of engagement are key to sustaining momentum:** The Network created a robust plan to ensure that nurses would stay engaged once the website went live. For example, it organized webinars and workshops to attract nurses from different geographies, provided travel scholarships for in-person meetings, and added functionality to make the website interactive, including hosting a discussion forum and spotlighting different Network members each month.
- **It's important to recognize when to bring in help:** Understanding the limitations within the Network's own team helped set reasonable expectations for what it could achieve by itself. Ultimately, the Centre determined which services should be subcontracted and hired the technical support required for website development and management.

Goals & next steps

Immediate goals for the GNNRD are to build chapters in new geographies to establish national/regional networks and links to specialist disease groups to create a repository of resources specific to each disease. Nurses interested in leadership roles to represent their country or region, or a specific disease, can contact hello@gnnrd.org

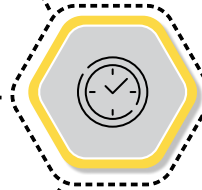
The near-term goals are to expand the Network to one thousand members by the end of 2024; establish an advisory group of patients with lived experience; refine a strategic framework to inform the Network's future direction, including clear goals and deliverables; and add more translation options for greater linguistic diversity.

Success factors & considerations when developing a similar model



Clearly identified need, ideally as part of a rare disease needs assessment

Respected organization willing to invest time and resources to meet that need and assume governance



Existing resources—national, regional, global—that can be leveraged to avoid reinventing the wheel

Partnerships already in place to provide expertise and credibility



Mechanisms in place for involving the beneficiaries in co-creating the solution

Channels to promote the initiative and ensure it reaches the target audience



Evaluation metrics and plan for course corrections in place

