



Advancing Global Nursing Education in Rare and Undiagnosed Disease

Introduction

The Global Nursing Network for Rare Diseases (GNNRD) recognises the urgent need to strengthen education for nurses and midwives worldwide in rare and undiagnosed disease (RUD). With over 300 million people affected globally, the burden of RUD is significant, yet education for nurses in this field remains inadequate and inequitable. Without targeted investment in RUD nursing and midwifery education, opportunities to improve early recognition, quality care and patient outcomes will continue to be missed.

Background

RUD is a global health priority. People living with RUD often experience a protracted diagnostic journey, fragmented care, lack of treatment options, increased mental health burden, stigma and isolation. This not only impacts patients and families but also places a heavy strain on health systems, where delayed diagnosis and fragmented care create inefficiencies and escalates costs. While each rare disease is unique, people living with RUD share common challenges that transcend individual diagnoses, making this a collective public health issue that requires systemic solutions.

Despite the collectively high prevalence of RUDs, awareness and education remain insufficient across healthcare professions. As the world's largest and most accessible health workforce (and often the only provider available) nurses are vital to improving rare disease outcomes. They deliver care across the lifespan, including screening, therapies and treatments, health education, care coordination and counselling. Nurses support RUD patients and their families in coping with a diagnosis (or lack of) and often evaluate and monitor psychosocial consequences throughout the care journey. During their careers, every nurse, across every setting, will care for patients with rare diseases.

The current gap in accessible RUD education is further driven by global inequities in learning opportunities, for example as nurses and midwives in low-income countries often have less access to professional development. By investing in nursing education, the impact extends beyond individual nurses to build stronger, more resilient health systems.

To make a meaningful difference, nurses and midwives who care for people living with RUD must be globally connected and strategically positioned to influence and advocate at local, national and international levels. Core to this is equitable access to education, resources, collaboration and research opportunities, as well as pathways to scholarships and funding. Embedded across the healthcare spectrum, from primary to tertiary care and across diverse specialties, nurses bring cultural insight and clinical expertise that, if equipped and empowered, can drive tangible change. Addressing this education gap is essential to improving health equity, aligning with the World Health Assembly Resolution on Rare Diseases (2025) and the United Nations Sustainable Development Goals (3 and 4).



Principles and Purpose

The position is grounded in the following values:

- **Equity:** All nurses, regardless of geography or resources, should have access to RUD education.
 - **Collaboration:** Global partnerships and knowledge-sharing are essential.
 - **Research and Best Practice:** Nursing education must be underpinned by evidence, integrating current research and global best practices while contributing to the generation of new knowledge.
 - **Valuing Lived Experience:** Education and resources should be co-designed with people living with RUD and their families, ensuring care is relevant and responsive to real needs.
 - **Patient and Family Centred Care:** Education should equip nurses to support patients and families holistically.
 - **Cultural Responsiveness:** Training must be adaptable to diverse health systems and cultural contexts.
 - **Nursing Leadership:** Nurses should be empowered and supported as leaders through high quality education, equipping them to drive policy, advocacy and system-level change in RUD.
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Position Statement

The GNNRD affirms that:

Delivering safe, high-quality, nursing and midwifery care for people living with RUD requires more than general clinical knowledge. It demands a distinct evidence base that reflects the specific needs of this population, as well as education programs specifically designed to equip nurses and midwives with RUD knowledge. Without targeted education and research, health professionals will continue to have knowledge gaps that will compound delayed diagnoses, fragmented care, and poorer outcomes.

Although each rare disease is uncommon, collectively they affect more than 300 million people worldwide. For this reason, the GNNRD affirms that all nurses and midwives require a foundational level of knowledge about RUD, regardless of where they practice. This knowledge must begin in undergraduate education and be reinforced through ongoing professional development, equipping nurses and midwives to contribute across the spectrum of care and services for people living with RUD.

As global leaders in nursing and midwifery practice for RUD (including clinical care, education, management, research and policy) the GNNRD has a pivotal role in defining the scope of practice and the essential knowledge and skills required. By embedding this expertise into education and leadership pathways, nurses and midwives can be empowered to drive change, advance evidence-based practice and improve outcomes for people living with RUD worldwide.



Commitment

The GNNRD is committed to:

- Empowering nurses and midwives globally to deliver safe, high-quality care and improve the lives of people living with RUD.
 - Building capacity through leadership, knowledge and skills, in partnership with people living with RUD and their families, to ensure care is grounded in both evidence and lived experience.
 - Developing learning programs, educational activities and resources that reflect best available evidence, are informed by real-world challenges, co-designed with lived-experience representatives and endorsed by GNNRD members with relevant practice and education expertise.
 - Ensuring equity of access by facilitating learning opportunities and resources that are accessible to nurses and midwives across diverse geographies and health systems.
 - Advocating for the inclusion of RUD knowledge as a core requirement for nurses and midwives, beginning in undergraduate education and continuing through ongoing professional development.
 - Providing resources and information to increase health literacy, awareness and understanding of RUD among nurses, midwives, patients, families and communities.
 - Advancing best practice in RUD nursing by supporting the translation and dissemination of research evidence to strengthen education and care globally.
 - Building leadership capacity through education, preparing nurses and midwives to engage in policy, advocacy and system design so they can influence rare disease services and advance health equity.
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Recommendations

We call for action from stakeholders at all levels:

Governments & Policymakers

- Drive the inclusion of RUD in undergraduate and postgraduate nursing and midwifery curricula through national education standards, accreditation requirements and regulatory frameworks, ensuring foundational knowledge for all graduates.
- Provide equitable funding pathways, scholarships and protected time for professional development, prioritising access for nurses and midwives in resource-limited settings.
- Recognise and embed nursing leadership in rare disease strategies, workforce planning and national health policy.

Education Providers

- Embed specialised, evidence-based content on RUD across nursing and midwifery programs, aligned with global best practice and informed by lived experience.
- Expand accessible continuing professional development (CPD) opportunities, including online modules, mentorship and exchange programs, with emphasis on RUD.
- Ensure education is fit-for-purpose and culturally responsive, adaptable to diverse health systems and patient populations.



Recommendations continued:

Health Service Providers

- Embed structured workforce education in RUD, including orientation, training and ongoing learning linked to clinical competencies and quality frameworks.
- Maintain up-to-date RUD clinical guidelines and resources for staff.
- Create opportunities for nurses and midwives to lead service design, care coordination and advocacy for people living with RUD.
- Co-design care models and resources with patients and families, ensuring psychosocial support and holistic approaches are embedded in care delivery.

Nurses & Midwives

- Engage in lifelong learning on RUD and apply knowledge across all care settings and specialties.
- Partner with patients and families to co-design education, resources and services that reflect lived experience.
- Champion policy, practice and research initiatives that advance recognition, equity and quality care for people living with RUD.

Conclusion

Education is the foundation for change. By equipping nurses and midwives with the knowledge, skills and leadership to address RUD, we can transform outcomes for millions worldwide. Equitable access to high-quality nursing and midwifery education will drive earlier recognition, better care and stronger health systems. Every nurse, in every setting, will encounter people living with RUD. By investing in RUD nursing education, we invest in hope, equity and better futures for patients, families and communities. GNNRD stands ready to lead this movement, however success requires the commitment and action of governments, educators, health services and the profession itself. This is both an urgent priority and a collective responsibility - through shared commitment and action we can build a future where nurses and midwives are fully prepared to deliver informed, compassionate and transformative care for all people living with RUD.

Approval Statement

This publication was endorsed by the GNNRD Education & Learning Committee: **December 2025.**



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