Enhancing Rare Disease Management Through Digital Tools and Education using simulated clinical cases

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Introduction

Rare genetic disease (RD) management is challenging, especially in **Latin America**, home to nearly 25% of the global rare disease population. Challenges include:

- Limited healthcare resources,
- Shortage of specialists (geneticists, genetic counselors),
- **Long waiting times** for specialist appointments.

Nurses often serve as the **first point of contact** for patients, making their role crucial in early symptom detection, family support and referrals to specialists

Rarus Health is a digital ecosystem that operates as a **Digital Care Center** for families and a **Multidisciplinary Team Assistant** for Healthcare Professionals (HCPs)

Our Platform as a Service collects consented real clinical data, which we enhance using AI to guide families and healthcare professionals, while also providing educational support.

Objectives

- 1. **Develop a comprehensive educational course** that provides pediatric nurses with the necessary skills and knowledge to manage patients with rare or undiagnosed diseases.
- 2. **Measure the level of knowledge** among participants before and after the course to assess learning and knowledge retention.
- 3. **Collect real-world clinical practice data** from the participants to better understand the current landscape of rare disease management in nursing and identify areas for improvement.

Methods

The educational curriculum we developed was based on:

- 1. **Professional nursing standards (NANDA, NIC, NOC),**
- 2. **Scientific literature** on rare diseases,
- 3. **Simulated clinical cases**, built using anonymized, consented data from the Rarus Health Platform.

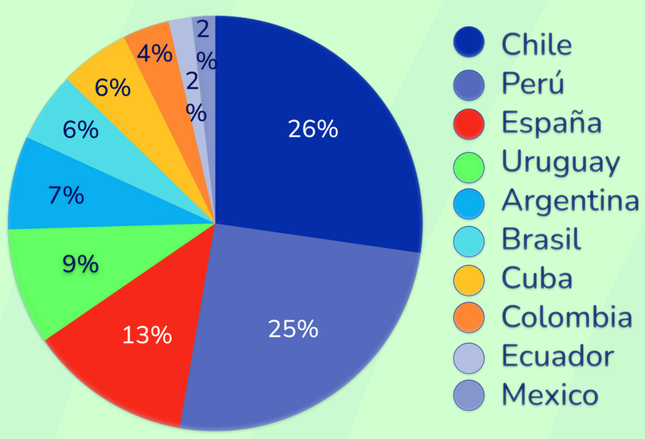
The course consisted of **five online webinars**, pre- and post-tests and a **final project** for practical application.

The **simulated clinical case** component on our platform provided patient dashboards with comprehensive medical and social information.

Delivered in partnership with **RED ENSI**, the largest nursing network in Latin America, to maximize reach and engagement.

Results

Diverse participation & outcomes



- Exceptional learning outcomes: **250%** knowledge improvement according to post-course test,
- Strong satisfaction: **4.95** Net Promoter Score (NPS).

Highly experienced nurses are interested in RD knowledge

The average nursing experience of participants was close to **14 years**, with **25%** of participants having between **18 and 24 years** of experience in the field.

High engagement

Interactive elements fostered a collaborative learning environment. **Simulated clinical case** attendance achieved **87%**.

Final projects covered

- Legislation and clinical guidelines for RD in home country,
- Personal experiences with affected families,
- Proposals for improving RD management.

Semantic analysis of submitted projects allowed us to **tailor our future collaborations with nurses,** focusing on addressing the key gaps in RD management and improving the quality of life for affected families.

Conclusion

- At Rarus Health, we use digital health tech to empower HCPs in RD management through education and personalized care tools.
- Our simulated clinical cases and SaaS platform help nurses identify early signs of rare diseases and improve patient care through real-world data.
- By fostering an informed healthcare community, we're advancing rare disease management and improving professional-patient interactions.