

❖ **Repository and clustering use case:**

PROMs in reimbursement decision making process -

Vicky McGrath



Vicky McGrath,
Chief Executive



RD Catalyst Award from Ireland's HRB (Health Research Board)

- Designed to create a more supportive environment in Ireland for rare disease Research & Innovation across
 - All rare disease areas
 - All settings (pre-clinical, clinical, population and health services research)
- Multi-stakeholder application includes
 - Patient organisations - Rare Diseases Ireland & EURORDIS
 - Irish ERN clinical leads - BOND, LUNG, ITHACA, ErkNET, Endo, SKIN
 - Irish delegate to the ERN Board of Member States
 - International collaborators

Collaboration with ERICA (WP3) will specifically:

- Enable evaluation of Patient-Centred Outcome Measures (PCOMs) and Patient Reported Outcome Measures (PROMs) as tools to support patient submissions for reimbursement decision making for orphan medicines (OMPs) by Irish authorities.
- Operate as a pilot project in the ERICA consortium demonstrating the real-world use of PROMs/PCOMS in reimbursement decision making.
- Align RD Catalyst work and outputs with the work already underway at ERICA.

Link with ERICA WP3 work:

- Help identify PROMs/PCOMs from their cataloguing work where OMP is designed for RD that already has a PROM/PCOM in place.
- Help identify potentially suitable PROMs/PCOMs associated with a 'cluster' of RDs when OMP is designed for RD in that cluster.
- Enable dissemination of work as a pilot project through ERICA consortium.