

2020 Member Feedback

Capacity Building and Advocacy



RARE
DISEASES
INTERNATIONAL

2020 Member Feedback

Capacity Building: Tools and Topics

Advocacy: Priorities - UHC - SDGs 2030

21 Participants

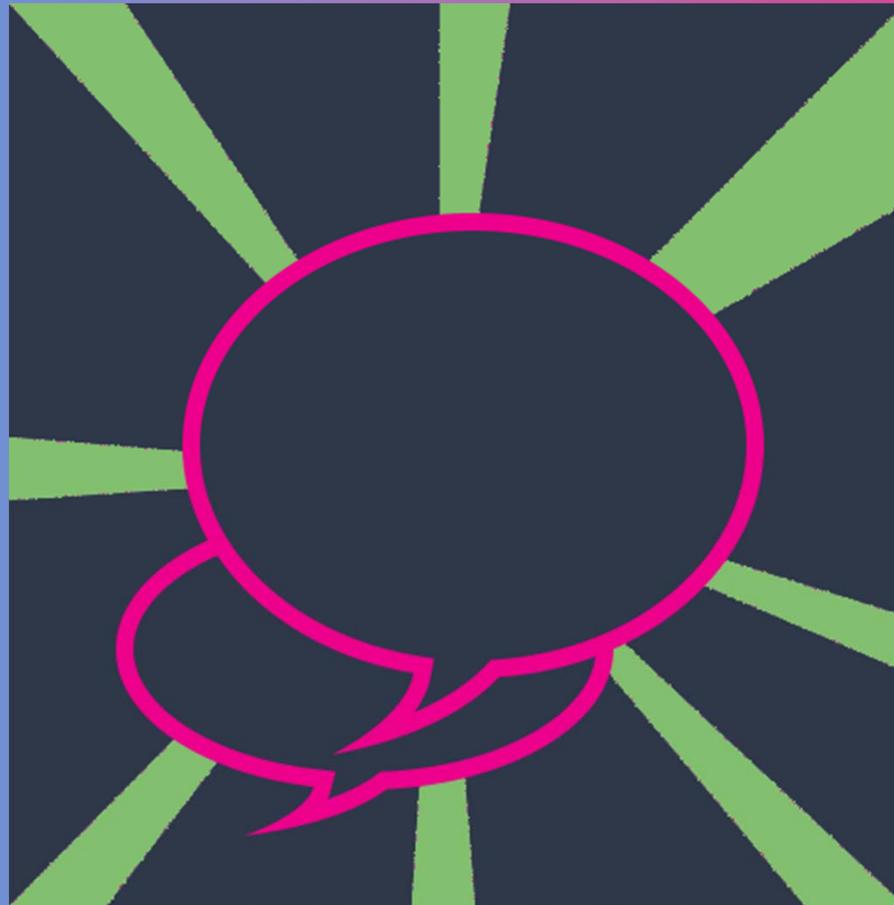
20 Questions: Multi-choice & Open Questions

First RDI Members Survey

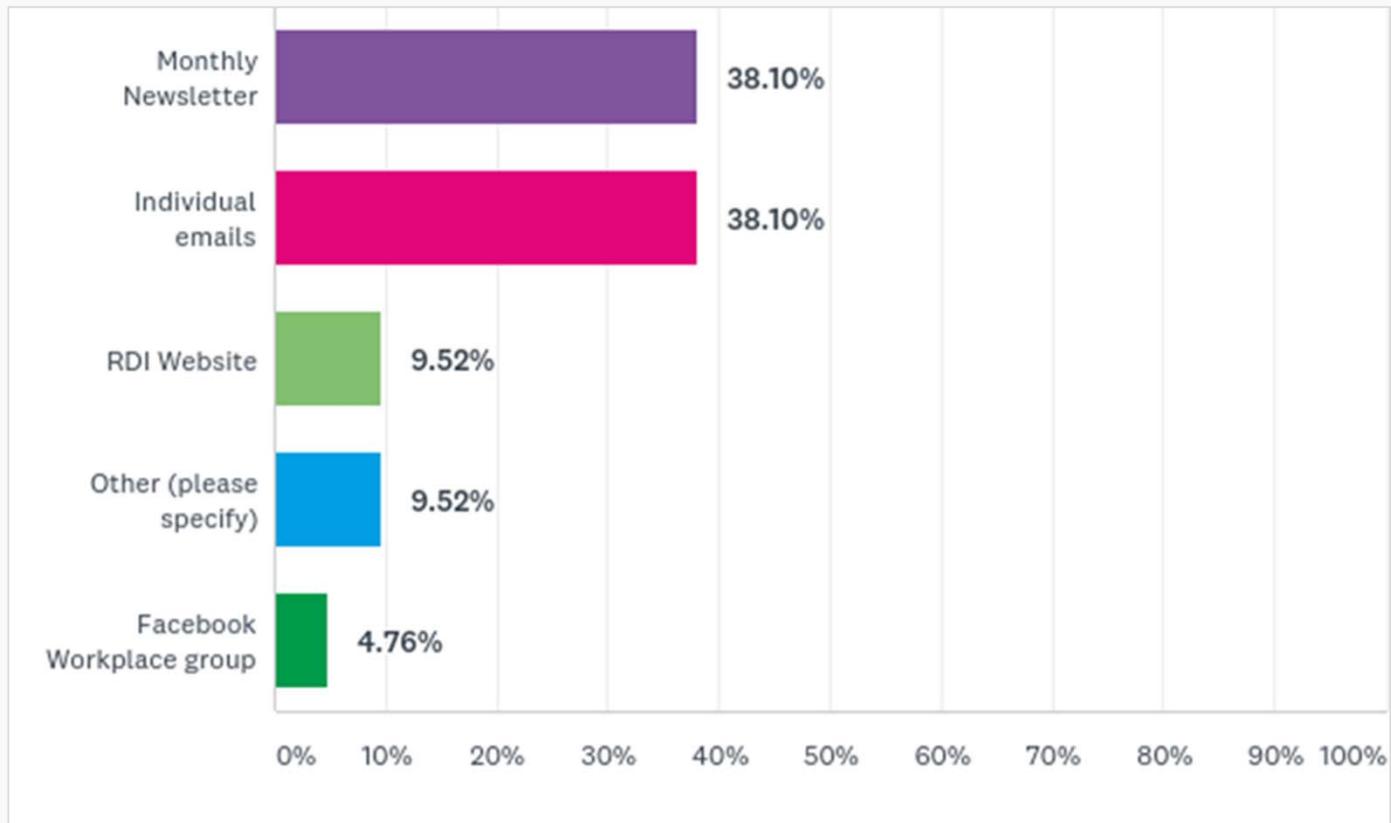
15 Countries & Six Continents



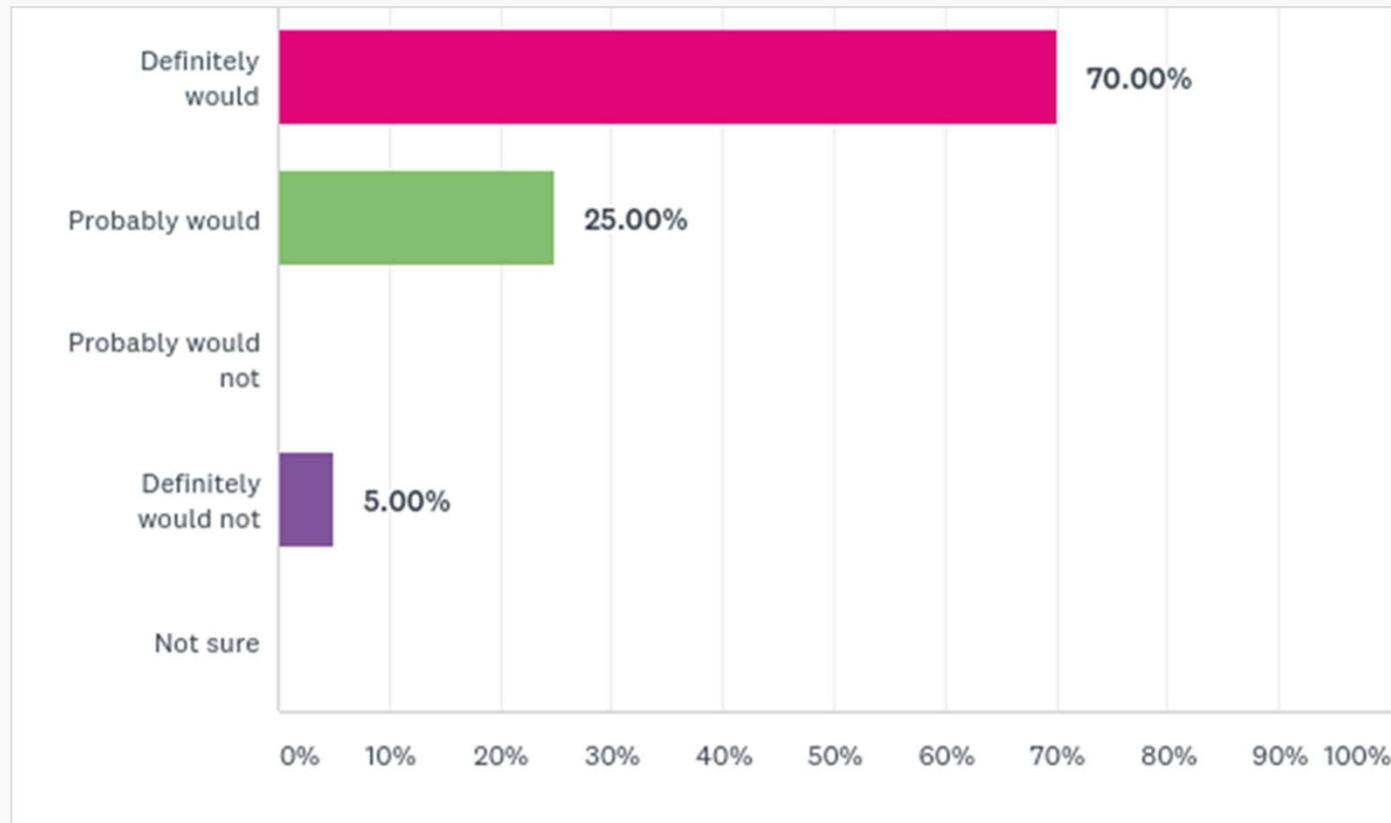
Capacity Building and Knowledge-Sharing



How do you receive news from RDI ?

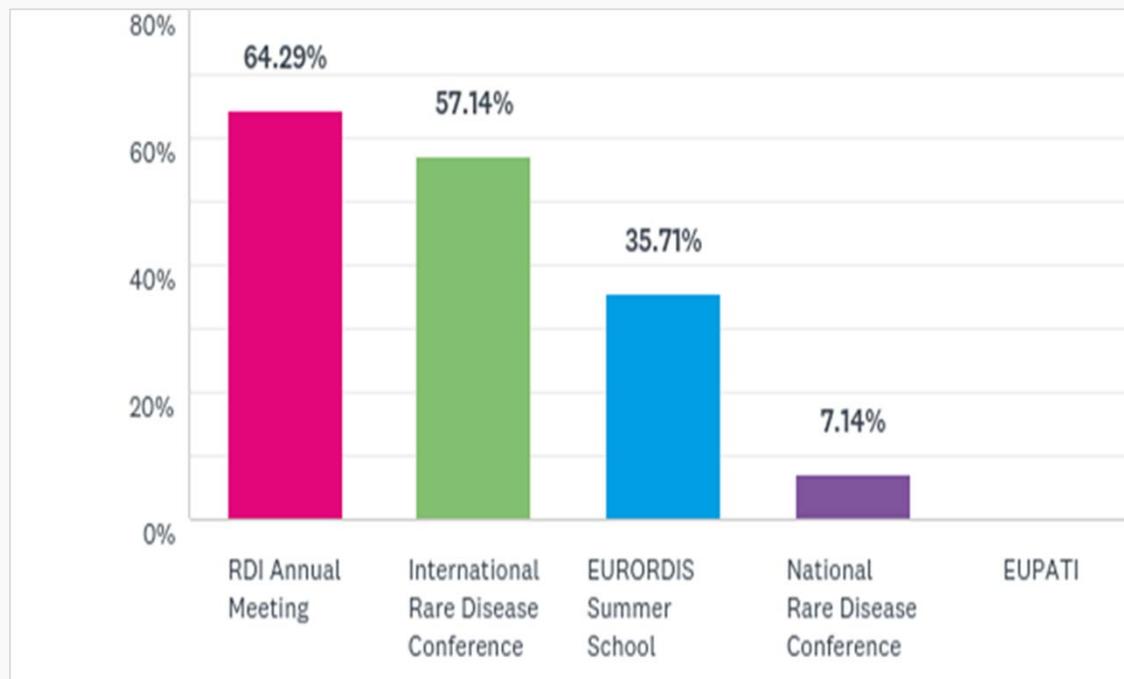
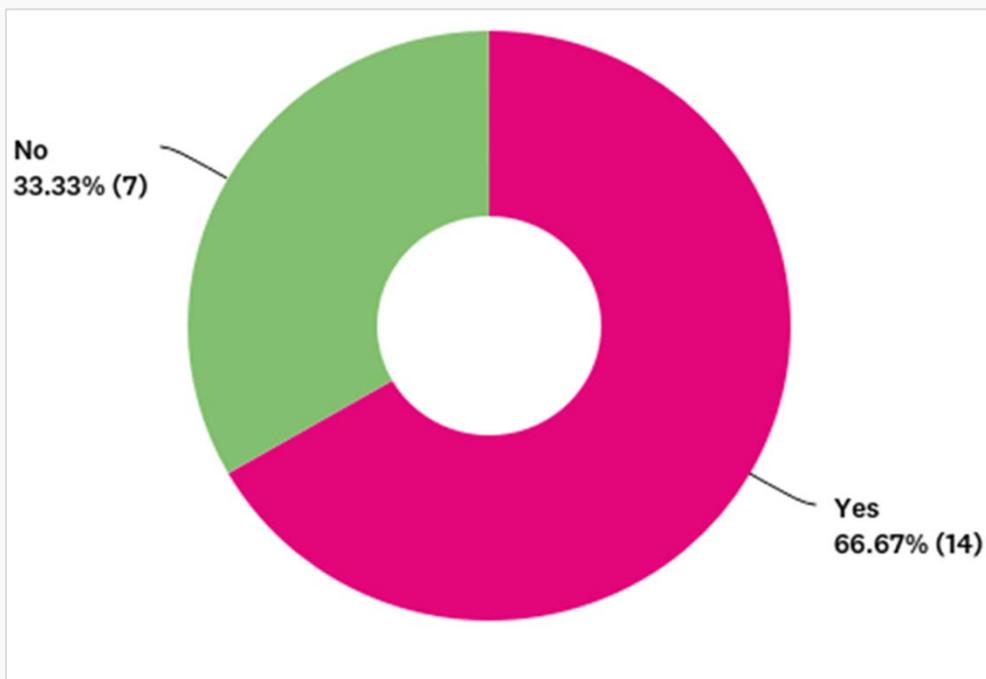


Would you like assistance to help build capacity ?



Have you ever received an RDI fellowship to attend a rare disease event/training session ?

Which event/training session ?



How would you prefer to share knowledge and experiences with other members ?



How would you prefer to participate in training/capacity building on RDI's activities?

Preferred Method of Participation	Ranking
Face to face meetings and training workshops	1
Being put in direct contact with an expert on a given topic	2
Webinars / Virtual meetings	3
Information packs or toolkits (fact sheets, communication templates)	4
Pre-recorded videos	5

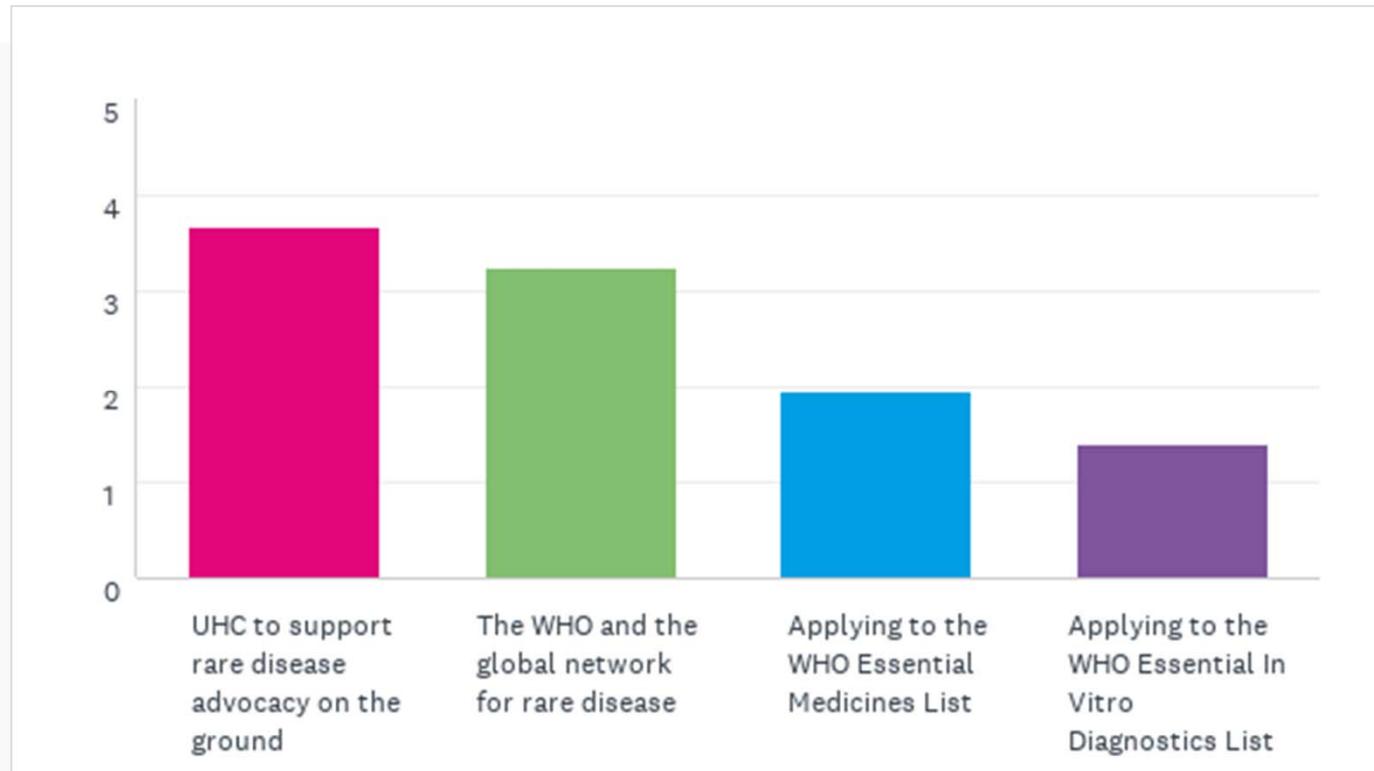


Which capacity building topics would most interest you ?

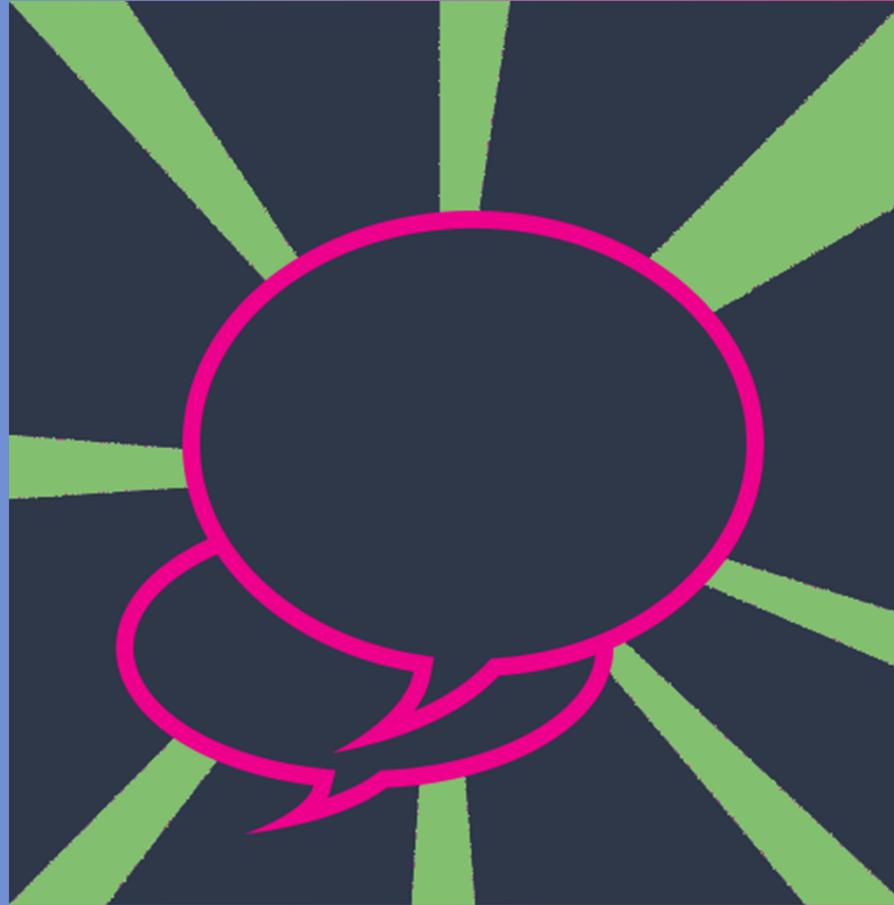
Topic	Interest
National advocacy and rare disease national plans	60%
International advocacy and international collaborations	45%
Organizational development and sustainability	30%
Access to medicines	30%
Working with the WHO and international agencies	25%
Medicines, research, development and regulation	5%
Communication and social media development	5%
Digital health and assisted technologies	0%



Which 2020 RDI activity most interests you ?



Advocacy



What are your top advocacy priorities in 2020?

Medicine Regulation & Access

National Plans and Legislation

National Awareness Raising

An Official Definition for Rare Diseases

**International and Regional
Collaboration**

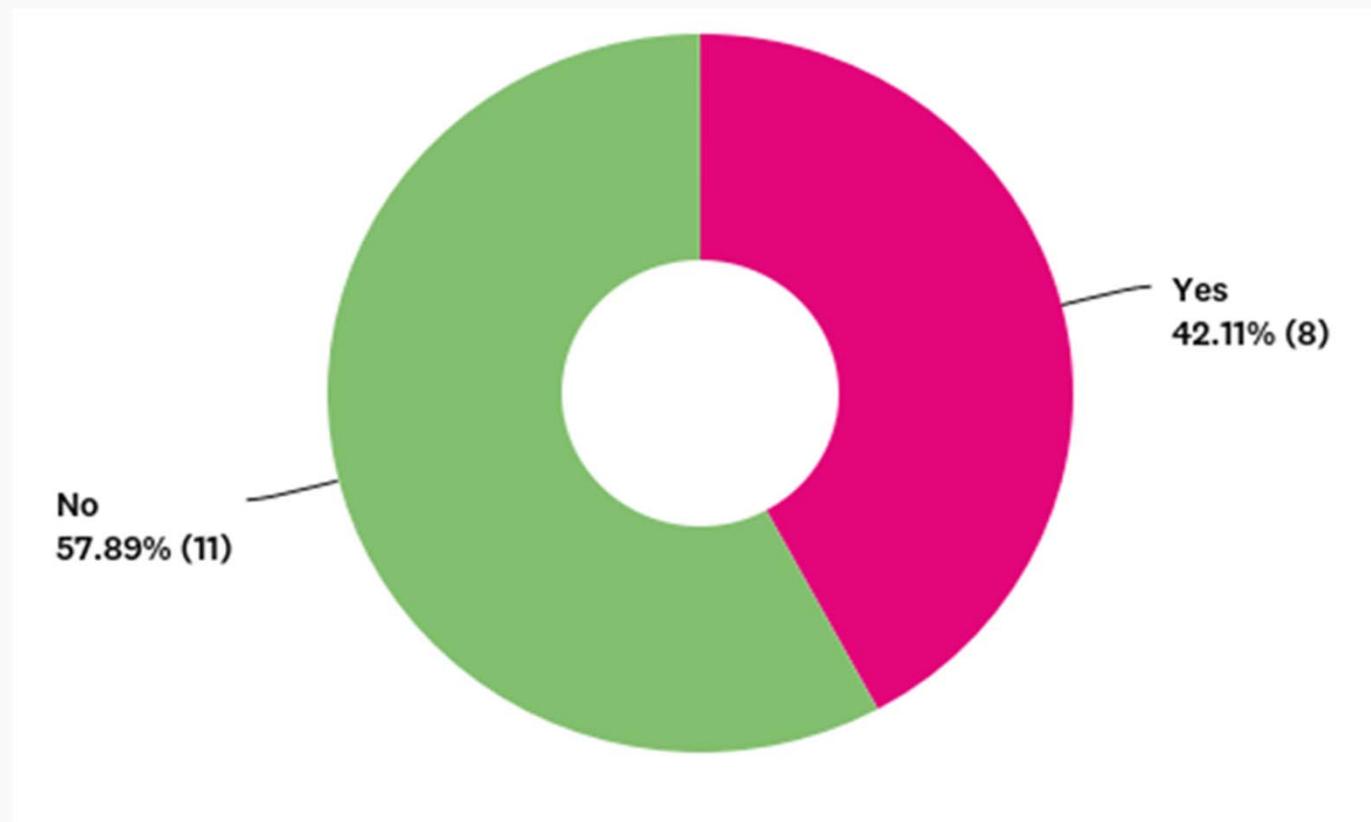
Diagnosis and Care

**Rare Diseases Patients in LMCs and
Rural Communities**

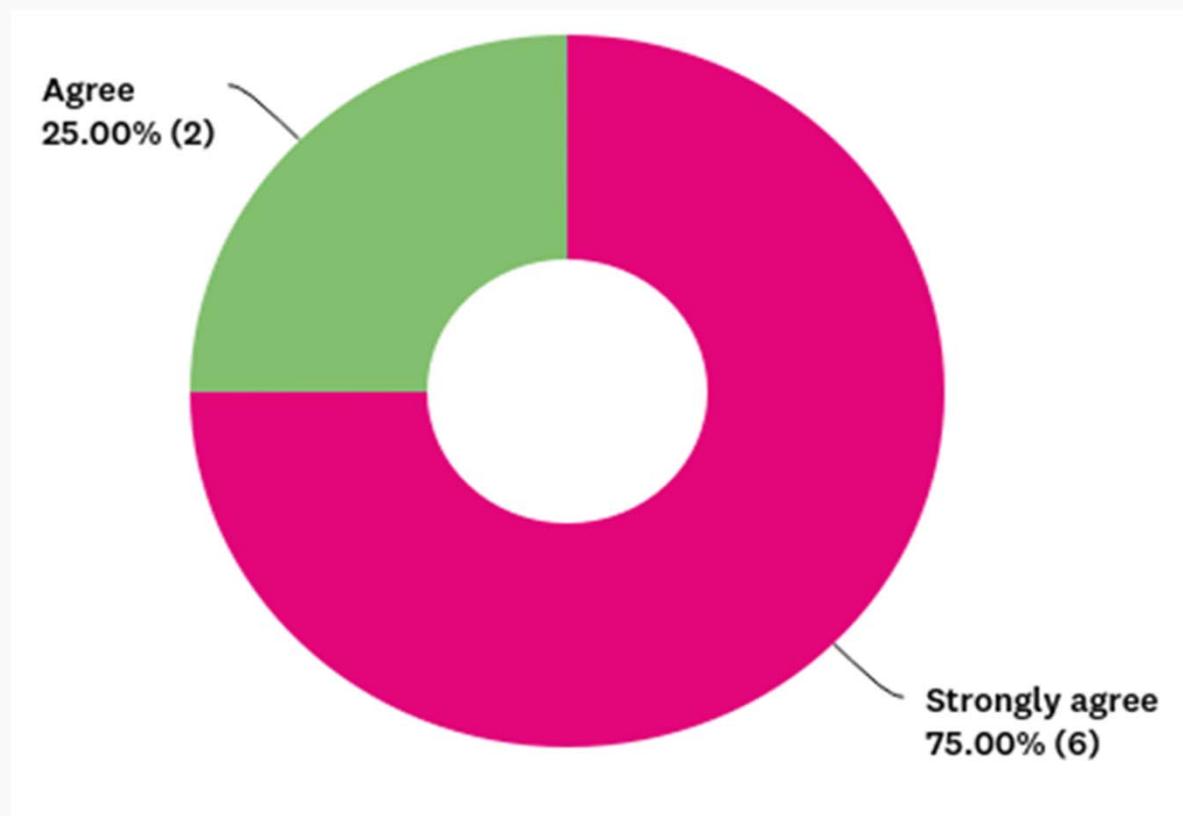


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Do you have an international advocacy plan/strategy ?



RDI is important to your international advocacy plan/strategy.



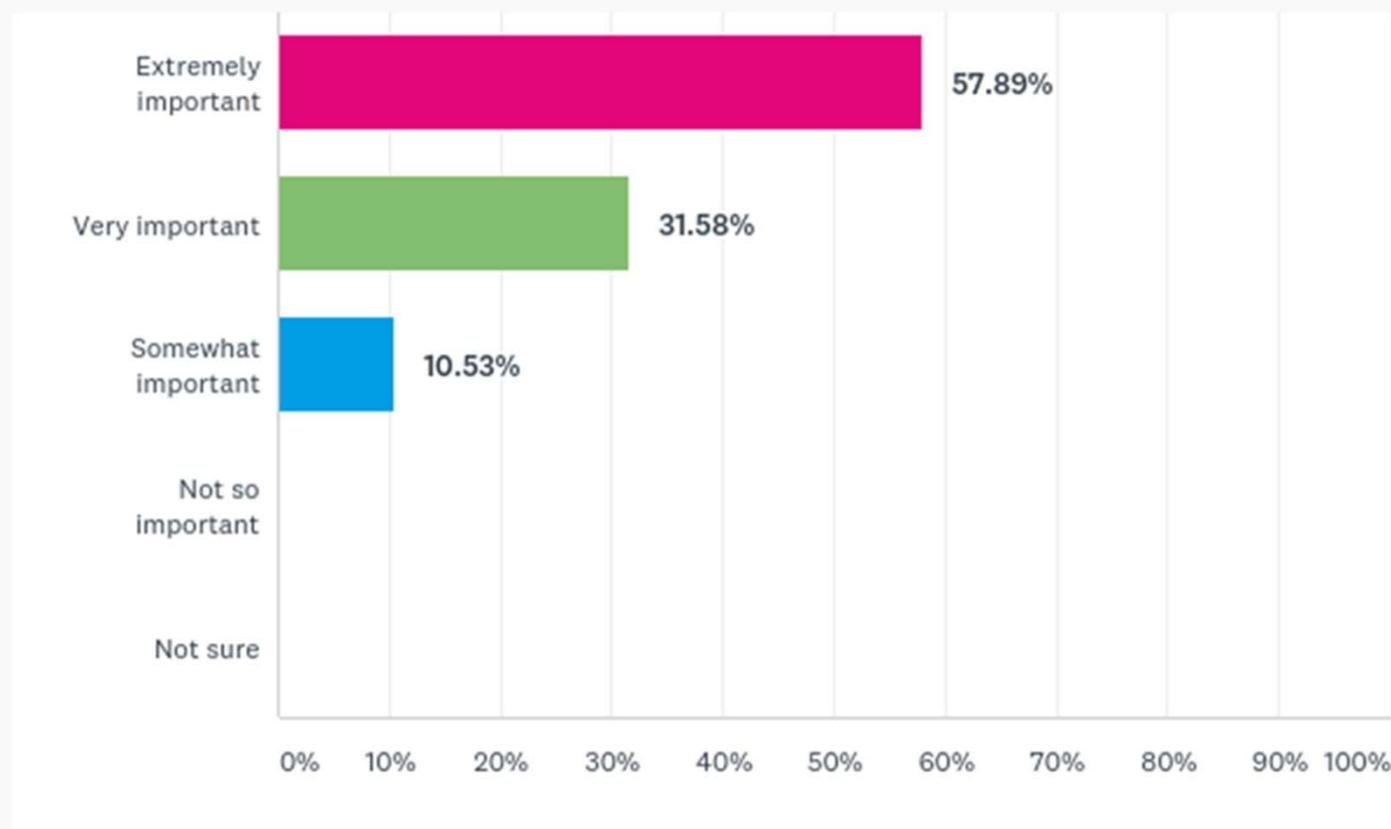
How does RDI contribute to your international advocacy plan/strategy?



- RDI helps us to publish research articles in the field of rare disease and exchange on activities with international patient associations
- Networking with other specific rare diseases groups to further enhance knowledge about international advocacy for rare diseases
- Increase the awareness of rare diseases in the UN and WHO context
- By plugging us into global initiatives (e.g. WHO)
- Analysing the situation -Identifying advocacy issues -Setting goals & objectives -Analysing policy & power -Identifying targets -Building added strength -Developing & implementing action plans
- By providing official declarations and statements related to the rights of patients with rare diseases



How important is the UN Declaration on UHC to your rare disease advocacy on the ground?



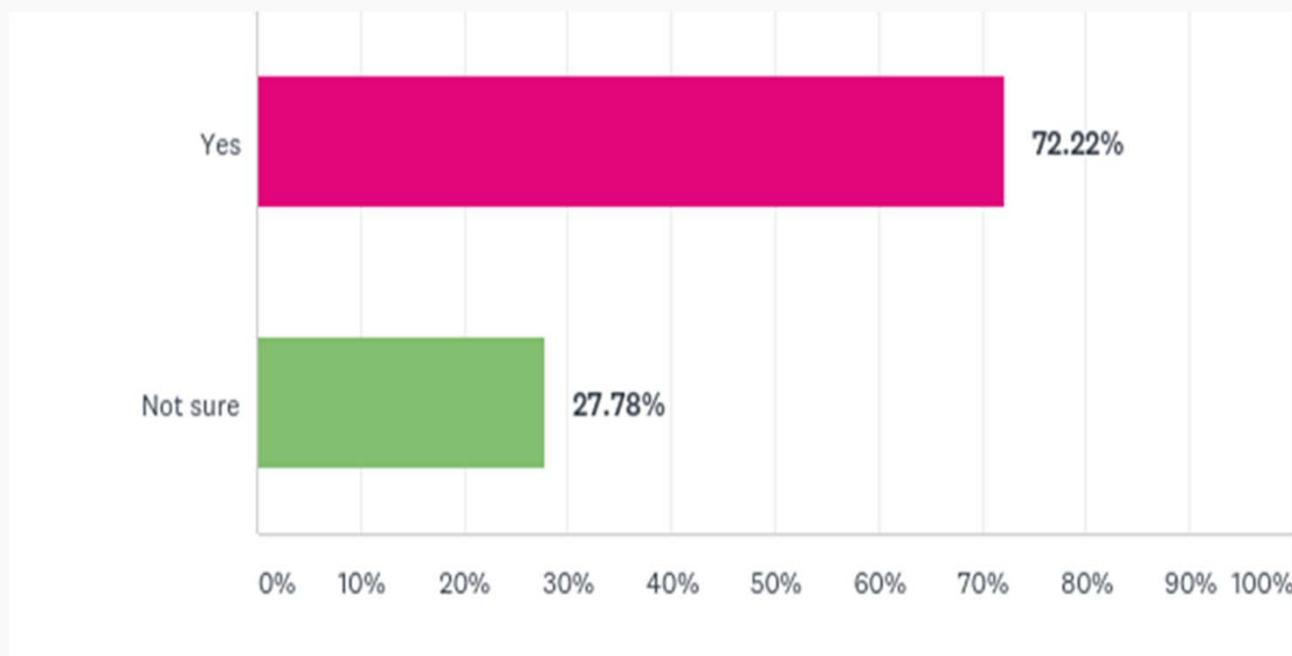
What impact does or could the UN Declaration on UHC have on your advocacy?



- It empowers us to ask government to respect universal and international agreements
- It is a great support on which to base our advocacy. But we don't use it enough
- A political declaration gives higher importance and endorses our work within the rare disease community
- Singapore has a very unique healthcare system. We do not know if the government will adopt Universal Health Coverage from the UN
- It provides a strong voice to encourage the local public health system to review healthcare for rare disease patients. It also attracts media interest and increases exposure.
- It gives rare disease a voice internationally and be a lever to improve RD patients' quality of life
- It supports negotiations with the pharma-industry
- It has a moderate impact



Can the UN's SDGs 2030 be used to advance international and local rare disease advocacy?



Other comments about RDI's capacity building processes and advocacy priorities?



Comments

- RDI could have programs to empower RD youth to be financially independent as they grow into adulthood
- RDI should develop a kit to organise national conferences on RD, international support is quite important
- RDI has to understand Asian culture in order to offer the right approach to this region.
- RDI could have different types of priorities including thematic priorities: scientific, technological and social priorities, as well as levels of priorities nationally and regionally. We could review the nature of priority setting process mechanisms
- In Asia I hope RDI can help to facilitate lowering the price of drugs through regional Trade Agreements between Government and Pharma companies e.g. through ASEAN, APEC

Questions

- Is RDI able to work with or influence governments and health authorities in conjunction with WHO, to establish funding and legal protection for all patients with rare diseases?
- Does RDI have rules for ultra-rare diseases?

