



Member Code of Conduct

Introduction

This code of conduct outlines the expectations of the RARE.Qc Network for all its members. Establishing a code of conduct is a vital step for the RARE.Qc Network to uphold ethics, professionalism, and foster a positive and collaborative environment.

Code of conduct content

It contains policies, behaviors, and consequences that aid in avoiding any conduct violations. It serves as a roadmap for all network members, helping them understand their expected participation in the Network and what constitutes a violation of the Network's policies.

Membership status

The status of each member is **reviewed every two years**; and the absence of any scientific activity or contribution within the Network for a period of two (2) years may result in a change of status or termination of membership. However, if they resume their research activities, they may again apply to join the Network.

Participation

Regular* and student* members must contribute to the vitality of the Network by:

- Participating in the RARE.Qc governance as a committee member, working group member, and/or participant to one or more RARE.Qc initiatives
- Sharing valuable rare disease expertise (i.e., SOPs, technical guidance, clinical data, research material, training material) within a collaborative framework
- Collaborating in the Network's planning and evaluation activities by providing the information requested by the Network, such as their updated publication list (through ORCID account), CV, documentation on research grants awarded, progress reports and other data that would benefit RARE.Qc members.
- Acknowledging the Network's contribution as a co-author in academic products (including, but not limited to, presentations, publications, posters, abstracts, print/web educational material) that are possible through RARE.Qc-initiated collaborations, samples/data sharing made available to members, funding opportunities, knowledge exchange and dissemination of ideas, or other similar activities. **The acknowledgment of RARE.Qc as a co-author allows the Network to track important performance measurement indicators, and add to the Network's vitality, visibility, credibility and outreach.** Please use **ORCID ID 0009-0009-1928-1598** where possible.
- Agreeing to abide by the FRQ [Policy on Responsible Conduct in Research](#).

Partner* members must contribute to the vitality of the Network by:

- Participating in the RARE.Qc governance as a committee member, working group member, and/or participant to one or more RARE.Qc initiatives
- Sharing valuable rare disease expertise (i.e., lived experience, guidance in mobilizing a specific community, international collaborations)

*Refer to page 11 of the [FRQS Guide](#) for member category definitions



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- Connecting members to valuable rare disease expertise and/or funding opportunities to promote knowledge generation, acceleration and/or use.
- Acknowledging the Network's contribution as a co-author in published products (including, but not limited to, presentations, publications, posters, abstracts, print/web educational material) that are possible through RARE.Qc-initiated collaborations, samples/data sharing made available to members, funding opportunities, knowledge exchange and dissemination of ideas, or other similar activities. **The acknowledgment of RARE.Qc as a co-author allows the Network to track important performance measurement indicators, and add to the Network's vitality, visibility, credibility and outreach.** Please use [ORCID ID 0009-0009-1928-1598](#) where possible.
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Guiding Principles

- Promote consideration for and human rights of all populations affected by rare diseases.
- Participate openly and transparently.
- Demonstrate a sense of respect of opinions, diversity and responsibility toward one another, RARE.Qc members and the public.
- Respect and maintain the confidentiality of information gained through your role as RARE.Qc member, including but not limited to internal documents, or individual personal information about persons affected by rare diseases.
- Not attempt to gain financial advantages while participating in RARE.Qc activities.
- Only speak on behalf of RARE.Qc when the appearance or participation has been preapproved by the RARE.Qc Management Committee.
- Share resources (i.e., data, samples, SOPs) in a collaborative manner.
- Respect and abide by any agreements or data sharing policies in place

What is considered unacceptable behaviour?

Unacceptable behaviour is any behaviour (actions/comments) that directly or indirectly harms another person or creates an unsafe or hostile environment for any person. This includes:

- Inappropriate actions, comments or speech concerning a person's background, including but not limited to a person's race, gender, sexual orientation, ethnicity, religion or any other aspect.
- Any form of racism, discrimination, sexual harassment, intimidation, or any form of unwelcome solicitation of emotional or physical intimacy.
- Inciting or spreading hatred or violence.
- Using one's position or authority in a way that is considered inappropriate.
- Advocacy of, or encouragement of any of the above behaviours.
- Scientific misconduct, including the use of data or material from another investigator, (whether they are a RARE.Qc member or not) without explicit consent from the latter



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Acknowledgement of FRQS support in the common CV

The FRQS recommends that network directors, axis leaders and members receiving a network grant indicate this in their joint CV, in the “research funding” section.

For other regular, student and partner members, it is suggested that they indicate their RARE.Qc network affiliation in the “Detailed contributions” document, in the “Activities and contributions” section.

Breach or violation of the Code of Conduct

A breach or violation of code of conduct, is any action that goes against the network's established policies and guidelines, either intentionally or unintentionally. These violations can be categorized as workplace code of conduct violations and professional code of conduct violations, each with its own set of consequences. Recognizing and understanding these categories aids network members in complying with the Network’s code and upholding a professional work environment.

How will violations be evaluated and consequences?

Violations of the above Code will be evaluated firstly by the relevant institution where the alleged violation may have occurred and in situations where the violation may negatively impact the RARE.Qc Network, by the RARE.Qc Management Committee. Potential outcomes of code of conduct violations may include verbal or written reprimand, suspension or dismissal from the Network, and legal consequences. The FRQS may revoke membership for irresponsible research conduct.

Signature

By signing below, I have read and understood the RARE.Qc Code of Conduct.

RARE.Qc member printed name

Signature

Date (DD-MM-YYYY)