



**International Council of
Cardiovascular Prevention
and Rehabilitation (ICCP)**

**International Cardiac Rehabilitation Registry (ICRR)
User Sub-Committee**

Terms of Reference

V1; November 9, 2020

The goal of the ICRR is to evaluate cardiac rehabilitation (CR) delivery (e.g., describe care patterns, variations in treatment and outcomes) and enable quality improvement in low-resource settings (defined as per M. Heine et al.), with the aim of ultimately improving patient outcomes. Access and equity will be considered.

1. ORGANIZATIONAL STRUCTURE, AUTHORITY AND ACCOUNTABILITY

As per the ICRR organizational chart, the ICCR User sub-Committee reports to the Steering Committee. The ultimate authority for the ICRR is the ICRR Executive committee of the Steering Committee, with approval from and accountability to ICCPR Executive.

2. MEMBERS

The user sub-committee shall be comprised of CR clinicians involved in the registry from all regions of the globe (as many from all 6 as possible), primarily in a low-resource setting, as well as at least one CR patient participant at a registry site who has agreed to provide patient-reported data. Members should represent the diversity of disciplines delivering CR (e.g., nursing, physiotherapy, medicine). Other sought expertise includes: quality improvement, registries (e.g., best practices in site on-boarding, ethics) and patient engagement.

The sub-committee shall be comprised of 2 co-chairs (1 focused on on-boarding sites and the other on quality improvement), the trainee secretary from the steering committee, at least 1 patient partner, and a minimum of 2 other members (i.e., minimum 6 members). One chair shall serve on the ICRR steering committee.

The Chair serving on ICCR Steering approves meeting agendas and minutes as drafted by the Secretary, chairs each meeting, guiding the meeting in accordance with the agenda and time available, while ensuring all discussion items end with a decision, action or definitive outcome. The chair serving on ICCR Steering shall provide an update on sub-committee activity each steering committee, and also report steering committee activity to the sub-committee each sub-committee meeting (ie., standing agenda items). The co-chair will serve this function in the event the chair has a conflict.

All members must be committed to upholding ICCPR's mission, as outlined in our Charter (<https://globalcardiacrehab.com/The-Charter>), and have the intention of participating in the ICRR. They will be asked to disclose any conflicts of interest.

Initial members will be invited from ICCPR Council (who may share the invitation with their association members) and friends. New members will be asked to provide context (i.e., in what way it is low in resources) as well as related expertise and experience (e.g., a few sentences and a CV). These will be considered by the Exec and co-chairs, and if more interested and eligible candidates are nominated than spots available, candidates will be elected through a vote. Thereafter, the user group shall be populated through invitation of CR programs participating in the registry, with again an aim to have representation from low-resource settings in each region of the globe, and nominations vetted by the user sub-committee.

ICRR Exec, with majority approval from the Steering Committee, may nominate members to serve as advisors if the user sub-committee identifies specific needed expertise.

All sub-committee members shall have the initial opportunity to publish data from the registry before it may be opened up to the research community at large and likely at cost, subject to the policy developed by the research sub-committee (including appropriate ethics approvals). User sub-committee members may be invited to co-author manuscripts stemming from the registry, if they make a contribution worthy of authorship in accordance with the principles of COPE (e.g., https://publicationethics.org/files/COPE_DD_A4_Authorship_SEPT19_SCREEN_AW.pdf).

3. TERMS OF OFFICE

The sub-Committee members will serve for a minimum of three years (half of initial members shall be asked to serve 2 years to stagger term ends and hence sub-committee member renewal/memory), with the possibility of renewal for a 2nd term. Sub-committee co-chairs shall serve for 1 year as past-chair upon term end; their term expiry shall be staggered. Terms of office are based on the calendar year.

4. COMMITTEE FUNCTIONS

- a. The remit of the user group is to engage sites to join the registry and support on-boarding, liaising with users for training to optimize data quality. Note that Dendrite is available for training on the use of the registry platform for all participating programs.

With regard to on-boarding, the user sub-committee shall implement Standard Operating Procedure (SOP) approved by the steering committee. The user group shall then support interested sites to join the ICRR, in accordance with the SOP.

Once all interested sites are on-boarded and supported in optimizing their data provision (i.e., generalizability, retention, data quality, quality improvement), eligible CR programs in under-represented regions will be actively approached to solicit interest in joining the registry.

- b. The user group shall also work with interested programs to improve CR quality where low, as identified in the ICRR dashboards. The user group shall hold a virtual meeting annually with participating programs to report on data quality, benchmarking, among other items of business.
- c. This sub-committee is the avenue for feedback by users to the registry for needed improvement. The user group shall communicate and support all participating programs shall changes be made to the registry.
- d. The sub-committee shall provide information to the research sub-committee for an annual registry report for various stakeholders, and assist in its' dissemination.

7. MEETINGS

The subcommittee shall meet thrice yearly at a minimum. Meetings shall be held virtually, at a time which coincides with business hours for the most members given their respective time zones. Efforts will be made for meetings to be held at a regular, pre-set re-occurring time.

The committee has a designated trainee secretary from ICRR to take minutes. Notice of meetings and circulation of meeting materials shall occur a minimum of 2 weeks in advance by the Secretary.

Technical or other experts may be invited to attend part or all of a meeting(s) as a guest at the request of the Chairperson on behalf of the sub-Committee to provide advice and assistance where necessary.

A quorum of members (10%) must be present before voting at a meeting can proceed. The sub-committee will make decisions by a simple majority+1 if consensus is not achievable. If a decision is required and a quorum is not present, the decision will be voted on by alternate means (e.g., eVote).

8. UPDATES TO TERMS

These Terms of Reference will be reviewed as needed, and no less frequently than every two years.