International Council of Cardiovascular Prevention and Rehabilitation (ICCPR)

International Cardiac Rehabilitation Registry (ICRR)
Steering Committee

Terms of Reference

V1; April 15, 2020

1. PURPOSE

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.

2. ORGANIZATIONAL STRUCTURE

As per the ICRR organizational chart, the ICCR Steering Committee shall be lead by an Executive Committee. From the outset it is conceived that the steering committee will have 2 regularly-meeting sub-committees (user group & research), with an ad-hoc group comprised of representatives of other CR registries internationally. The ICRR Steering Committee may change the sub-committee structure as the ICRR is developed.

3. AUTHORITY AND ACCOUNTABILITY

The ICRR Steering Committee is the governance body for development, implementation and conduct of the registry, under the approval of the ICCPR. The steering committee is lead by an Executive Committee, and will have 3 sub-committees as originally conceived.
The co-chairs of the ICRR Executive Committee are Drs. Sherry Grace (ICCPR Past-Chair, Canada) & Karam Turk-Adawi (ICCPR Friend, Qatar). The ICRR shall provide a formal written report to ICCPR upon request, but at a minimum of every 2 years.

4. MEMBERS

The steering committee shall be comprised of CR experts from all regions of the globe (as many from all 6 as possible). Members should represent the diversity of disciplines delivering CR. Other sought expertise includes: policy-making/ implementation science, registries (e.g., best practices, technology, privacy) and research (e.g., open data sharing, epidemiology, health informatics).

The steering committee shall be comprised of the 2 co-chairs, a trainee secretary, a treasurer, a representative from the sub-committees (once formed; preferably the chairs), and a minimum of 2 other members (i.e., minimum 8 members). At least one member shall be on ICCPR Executive if possible. The ICRR executive is comprised of the 2 co-chairs and the trainee secretary.

The user group shall be populated through invitation of CR programs participating in the registry, with again an aim to have representation from each region of the globe. A chair shall be selected by members, and be appointed to the steering committee. A trainee will serve as Secretary. The patient voice shall be represented in ICRR governance (user group).

The research sub-committee will be comprised of a minimum of 4 CR researchers with expertise in CR quality indicators, epidemiology, etc. Members should preferably hold advanced degrees (e.g., research-based master's or PhD). A chair shall be selected by members, and be appointed to the steering committee. A trainee will serve as Secretary.

The registry liaison group shall be comprised of named representatives from known CR registries globally, namely UK, Australia, Europe (Austria, Denmark), China, US. It shall be chaired by an ICRR Exec co-chair, and a trainee shall serve as secretary.

Each committee shall have a Chair who 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.

All members must be committed to upholding ICCPR's mission, as outlined in our Charter (https://globalcardiacrehab.com/The-Charter). Initial members were invited from ICCPR Council and friends. New members will be elected, following provision of context and expertise, through a vote of the Steering Committee. ICRR Exec with majority approval may nominate members to serve if they have specific needed expertise.

All steering committee and sub-committee members shall have the initial opportunity to publish data from the registry before it is opened up to the research community at large, subject to policies to be developed.

5. TERMS OF OFFICE

The 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 committee member renewal/memory), with the possibility of renewal for a 2nd term. ICRR Exec 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.

6. COMMITTEE FUNCTIONS

The remit of the ICRR Steering Committee includes: oversight, budget, initial development and launch, sustainability, ethics/privacy/security. The ICRR Exec will lead these activities with input and approval from the Steering Committee.

The remit of the user group is to engage sites to join the registry and support on-boarding, liaise with users for training and to optimize data quality, and provide an avenue for feedback by users for registry improvement. Note that Dendrite is available for training on the use of the registry platform for all participating programs. The user group shall also work with interested programs to improve CR quality where low. The user group shall hold a virtual meeting annually with participating programs to report on data quality, benchmarking, among other items of business.

The user group shall communicate and support all participating programs shall changes be made to the registry.

The research group shall develop and enact policies with regard to research data access and dissemination. Their remit will include data management (including liaising with user group regarding data quality improvement), data access, publications and presentations, and research program administration. With regard to data access, the research committee shall oversee ICRR Executive publication of the ICRR initial data, and then consider sharing data open access (pending privacy/ security approvals) or if not develop a process for scientists to apply for and gain access to ICRR data for dissemination to the research community.

7. MEETINGS

ICRR Exec shall meet monthly at a minimum. The steering committee and it's subcommittees shall meet twice yearly at a minimum (registry liaison is ad-hoc). 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.

Each committee shall have a designated secretary 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 Steering Committee to provide advice and assistance where necessary.

A quorum of members (10%) must be present before voting at a meeting can proceed. The SC 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.