International Cardiac Rehabilitation Registry (ICRR)
Research Sub-Committee

Terms of Reference

V1; March 22, 2021

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. https://oatd.org/oatd/record?record=handle%5C:10019.1%5C%2F109257), with the aim of ultimately improving patient outcomes.

1. ORGANIZATIONAL STRUCTURE, AUTHORITY AND ACCOUNTABILITY

As per the ICRR organizational chart, the ICCR Research 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 Research Sub-Committee will be composed of the Chair (who serves on the ICRR Steering Committee), a trainee secretary, and a minimum of 2 other qualified individuals, a knowledge user, plus a Database Analyst (i.e., minimum 6 members). The database analyst shall be a trainee until such a time that ICRR can support a paid biostatistician.

Inaugural representatives will be invited by the ICRR Steering Committee from the ICCPR community, or other known experts in the area. Subsequent vacant positions will be filled by the ICRR Research Sub-Committee through the same sources.

For all positions other than knowledge users, research experience and/or a research-related position is required. Research-based Master's or PhD degrees are preferred. Experience with databases and/or clinical research is an asset. Members should preferably reside in low-resource contexts.

The sub-committee, with majority approval from the ICRR Executive, may nominate members to serve as advisors if the research sub-committee identifies specific needed expertise.

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.

The Chair of ICCR Research Sub-Committee approves meeting agendas and minutes as drafted by the secretary. He/she 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 shall provide an update on sub-committee activity each steering committee meeting, and also report steering committee activity to the sub-committee each sub-committee meeting (i.e., standing agenda items).

The Secretary shall arrange all meetings, draft agendas and minutes, and support the committee in consideration and monitoring of data access requests and in their administration of the data quality policy. The database analyst shall support data quality processes, develop the annual report with direction from the sub-committee, provide input on all data access requests, undertake approved analyses.

All research sub-committee members shall have the initial opportunity to publish data from the registry before it may be opened up to the research community, through following the data access policy and application form. Research sub-committee members may be invited to co-author manuscripts stemming from the registry in their area of expertise, if they contribute to a degree worthy of authorship in accordance with the principles of COPE (Committee on Publication Ethics) and ICMJE (International Committee of Medical Journals Editors), as per CRediT (https://casrai.org/credit/#:~:text=CRediT%20(Contributor%20Roles%20Taxonomy)%20is,contribution%20to%20the%20scholarly%20output).

3. 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. Sub-committee chair shall serve for 1 year as past-chair upon term end. Terms of office are based on the calendar year.

4. COMMITTEE FUNCTIONS

The Research Sub-Committee shall provide scientific oversight of the ICRR. Their remit will include data management (including liaising with user group regarding data quality improvement), data access, dissemination (including an annual report), and research program administration. Other functions may be required as prescribed or agreed upon by the ICRR Steering Committee.

Regarding Data Management, the ICRR Research Sub-Committee will:

- Implement ICRR's Data Quality Policy data correction strategy to maintain ICRR data integrity standards.
- Review data quality regularly through ICRR's completeness reporting dashboard and in conjunction with the database analyst, in accordance with the ICRR Data Quality Policy to maintain ICRR data integrity standards.
- Consider any requests for revision to the data definitions or set of measures from users or other sources at least every 5 years, pending funding availability to update the ICRR and buy-in by contributing sites.

Regarding Data Access and Dissemination Management, the ICRR Research Sub-Committee will:

- Oversee ICRR publication of the initial ICRR data,
- Administer ICRR Data Access and Dissemination policy.
    - Evaluate data access and dissemination requests in a fair and transparent manner, in accordance with the associated policy. In instances where requests are outside the norm, or carry potential conflict of interest, the committee shall consult the ICRR Steering Committee.
- Develop an ICRR research report, annually or on an as-requested basis.
- Promote greater use of ICRR data, including consideration of eventual sharing of data open access in whole or in part (if privacy/ security requirements can be met)

With regard Research Program Administration, the ICRR Research Sub-Committee will:

- Provide strategic recommendations to the ICRR Steering Committee regarding the overall research program for the ICRR, including directions, priorities, implementation of findings, partnerships, potential resources required and evaluation criteria, as requested.

Note that the sub-committee shall only have access to aggregated data from all sites for purposes laid out in these terms and to meet the mission of the ICRR, including the following:

1. Where the information gained can help guide leadership decisions related to utilization of services, general performance of CR programs, and identify priority actions that may be needed to improve Registry utilization and/or ICCPR member association education.
    a. The Annual Report may lead ICCPR leadership to request additional queries of the aggregated registry data for organizational or quality improvement purposes.
2. Access to aggregated Registry data by the sub-committee is permitted to inform members, policy-makers, and potentially any future corporate partners of Registry activities.
3. Access to aggregated Registry data by the sub-committee is permitted to inform members, users, and policy-makers of general patient outcomes or performance related to quality improvement initiatives in which ICCPR may take part in or initiate.
4. Access aggregated Registry data by the sub-committee is permitted to address questions from policy-makers regarding general patient outcomes or program performance.
5. In instances where the Registry data is used by ICRR to recognize high-performing programs, individual programs will not be identified unless individual program permission has been granted prior to any public reporting.
6. In no case will ICRR release individual patient records or allow data to be released that could be used to identify individual patients or sites.

5. MEETINGS

ICRR Research Sub-Committee shall meet quarterly 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.

Notice of meetings and circulation of meeting materials shall occur a minimum of 2 weeks in advance by the Secretary.

Other ICRR Steering Committee Members, additional researcher, technical experts may be invited to attend part or all of a meeting(s) as a guest at the request of the Chair on behalf of the Sub-Committee to provide advice and assistance where necessary. They have no voting rights.

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