



WE  
MEASURE  
UP!

# ICRR

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ICCP R ' S  
I N T E R N A T I O N A L  
C A R D I A C R E H A B  
R E G I S T R Y

**FIRST ANNUAL  
REPORT**

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# A MESSAGE FROM OUR EXECUTIVE COMMITTEE

December, 2022

Dear Global CR Community:

The ICRR Executive, with special thanks to our Secretaries Carol Tran and Fabbihah Raidah, are delighted to share with you this first report on ICRR activities. We launched in Fall 2021, in the midst of the COVID-19 pandemic, yet nevertheless have had a productive year, reaching our goals, due to the great co-operation of the ICRR community.

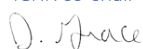
Prior to our launch, a rigorous process was followed to develop the ICRR, followed by usability testing. We then piloted the ICRR on-boarding and participation process with 5 sites. We are proud to report we now have 14 participating centers, and around 1300 patients entered. Annual patient assessments have recently commenced.

This year we have continued to liaise with national CR registries, including notably the Danish and Swedish registers. We have also engaged and trained close to 10 graduate students. We also launched ICCPR's corresponding Program Certification, which leverages registry data to enable quality assessment.

We are grateful to all contributing programs, as well as the many volunteers on our Steering Committee, as well as User and Research sub-committees. Read on to learn about their activities since registry inception!



Dr. Sherry Grace,  
PhD, FCCS, FAACVPR, CRFC  
ICRR co-chair

A handwritten signature in dark ink, appearing to read "D. Grace".

Dr. Karam Turk Adawi,  
PhD, MPH  
ICRR co-chair

A handwritten signature in dark ink, appearing to be stylized initials "KT".

# ABOUT THE ICRR & RATIONALE

Cardiovascular diseases (CVD) are among the leading burdens of death and disability globally. This burden is increasing at an alarming rate in low and middle-income countries (LMICs). Cardiac rehabilitation (CR) is an evidence-based secondary prevention model of care to mitigate this burden. And we know from ICCPR's Global Audit that the greatest need for programs is in LMICs.

In response to the ICCPR community, we developed the first-ever International Cardiac Rehabilitation Registry to support development of programs in LMICs and other low-resource settings. The aim of the registry is to promote cardiac rehabilitation quality to ultimately improve patient outcomes, but also advocacy and research.

With institutional approval, participating programs enter data on patients pre-program, post and annually thereafter, on ~ 30 variables. The many benefits for programs in participation are shown at the end of this report.

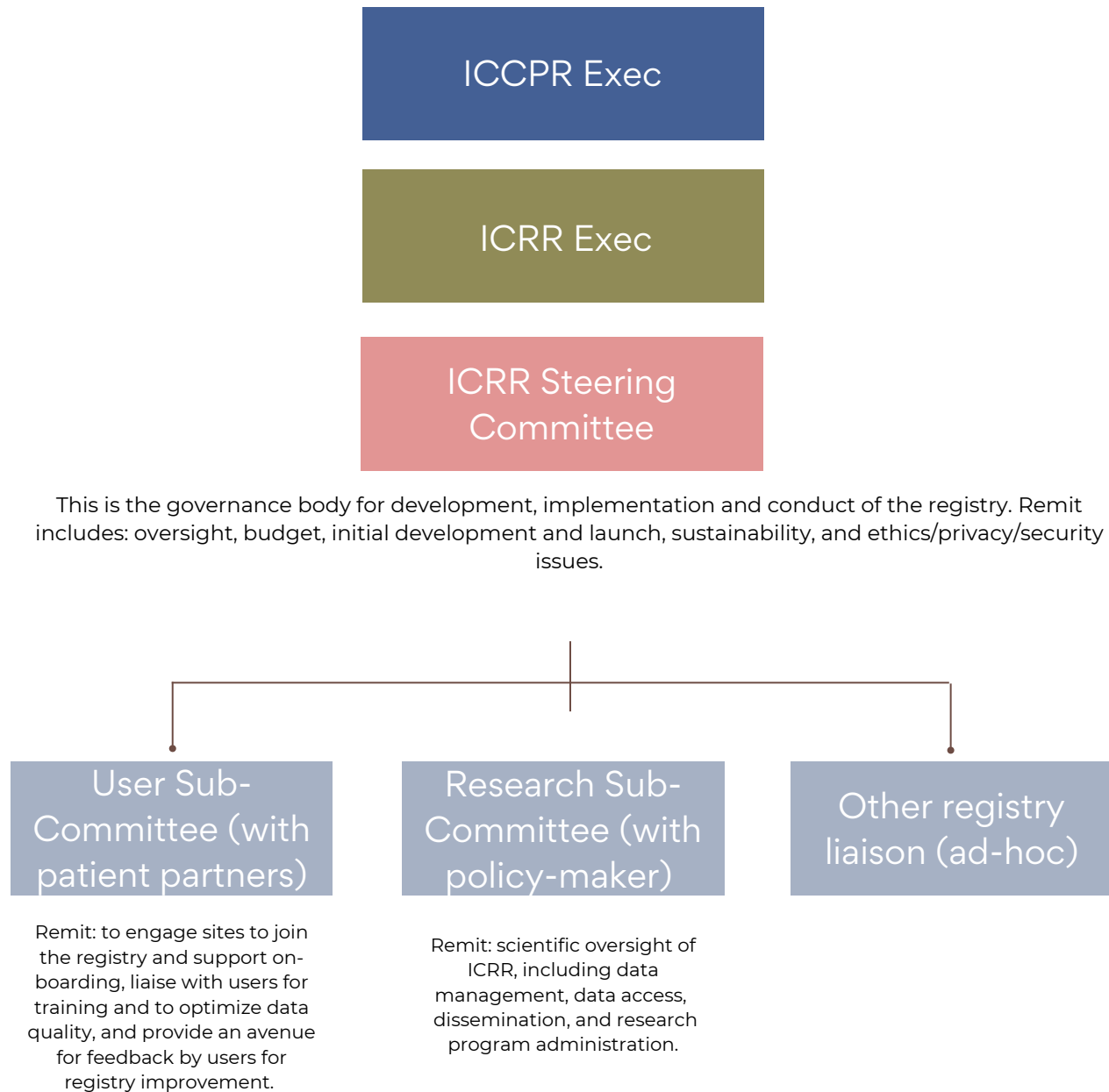
Patients are also considered in the ICRR. The patient voice is presented through the User sub-committee. Registry-participating patients can receive a lay summary at the end of their program, which shows their progress and outstanding areas to be addressed.



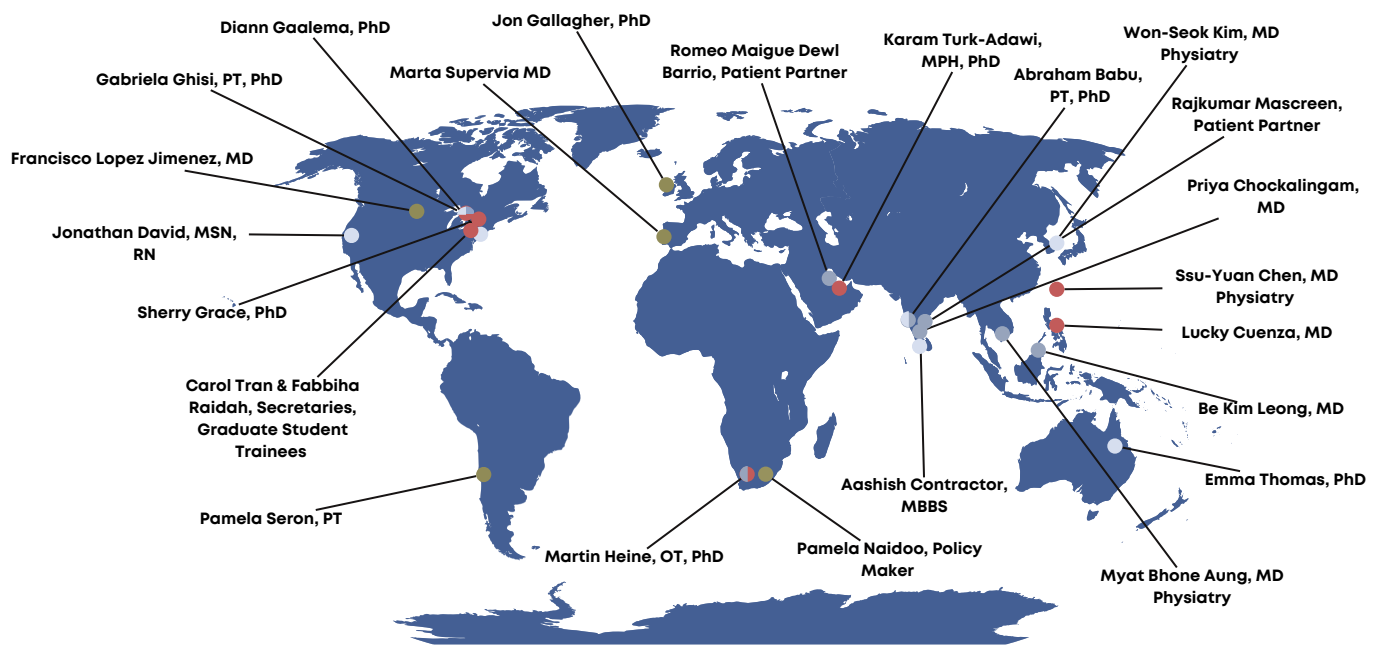
# ICRR GOVERNANCE

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## Committee Members



# COMMITTEE MEMBERS



- ICRR Steering Committee
- Research Sub-Committee
- User Sub-Committee
- ICCPR Program Certification Steering Committee

Our volunteers bring expertise from a wide range of relevant disciplines, across all regions of the globe.

# USER SUB-COMMITTEE

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## Activities:

The user sub-committee has on-boarded the 14 sites, and provided training this first year. They have met regularly to get input from programs and patients alike.

## On-Boarding Process:

After we receive both site institutional approval on our agreement and ethics waiver or approval (as applicable), the Secretary secures ICRR logins for the site data steward(s).

The ICRR secretary and user sub-committee chair then hold one of two 1.5 hours training sessions over video-conference with the data stewards of the site. During this call, the site data steward enters pre-program data for a patient privately, to troubleshoot any challenges. Any challenges with patient report (if opting in) will also be addressed. Minutes are provided to the site, with a recording of the session.

Based on the length of the program, a second on-boarding training is then arranged with the site, to support post-program / follow-up data entry training. At this time, sites are also oriented to the various other features of the registry to support quality improvement, research if interested, etc.

## ICRR Training:

This year, based on request from participating members, several training sessions were held. They are each available on our website on-demand for participating programs:

1. Introduction to the registry and pre-program assessment data entry  
[https://www.youtube.com/watch?v=YQ8EFME\\_RdE](https://www.youtube.com/watch?v=YQ8EFME_RdE)
2. Post-program assessment data entry and registry features  
[https://www.youtube.com/watch?v=A\\_x7f9wk3Ec](https://www.youtube.com/watch?v=A_x7f9wk3Ec)
3. Registry features for quality assessment (program and patient-level)  
<https://www.youtube.com/watch?v=4le3m17NUpU&feature=youtu.be>
4. Annual assessment data entry, evaluation and ending registry participation  
<https://www.youtube.com/watch?v=orb1HRxKfws>



# RESEARCH SUB-COMMITTEE

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## Activities

At their regular meetings, since inception, the sub-committee has finalized Terms of Reference and ICRR policies, such as for Data Access and Publications. Data quality is monitored, and a data quality audit process was operationalized, with discussion on communication with participating centers.

## Data Quality:

### Policy:

The quality of ICRR data is fundamental to achieving its aims, including data accuracy and completeness, as well as generalizability, validity, and reliability. The aim of the data quality policy is to ensure the utmost scientific integrity of the ICRR data and hence the credibility of derived conclusions. The main aspects of this policy are site training, a design of ICRR to promote data quality, data completeness and retention, data quality audits, as well as data rectification, including corrective and preventive actions.

[https://globalcardiacrehab.com/resources/Documents/ICRR\\_Policy\\_Data%20Quality\\_v1-clean.pdf](https://globalcardiacrehab.com/resources/Documents/ICRR_Policy_Data%20Quality_v1-clean.pdf)

### Reporting:

In the pilot sites, based on volumes at each program, 86% of referred patients were entered into ICRR monthly, and 99% of patients consented to participate. Pre-program variable completeness ranged from 91-100% (except for lipoproteins at 40%).

The proportion of patients with any follow-up data was 84.8% among completers, with 43.6% of non-completers having any data entered other than completion status. Post-program data completeness was lower (61% to 98%), and this was lower in patients who had not completed the program, despite conventions provided in the data dictionary to collect these data points via the phone or online.

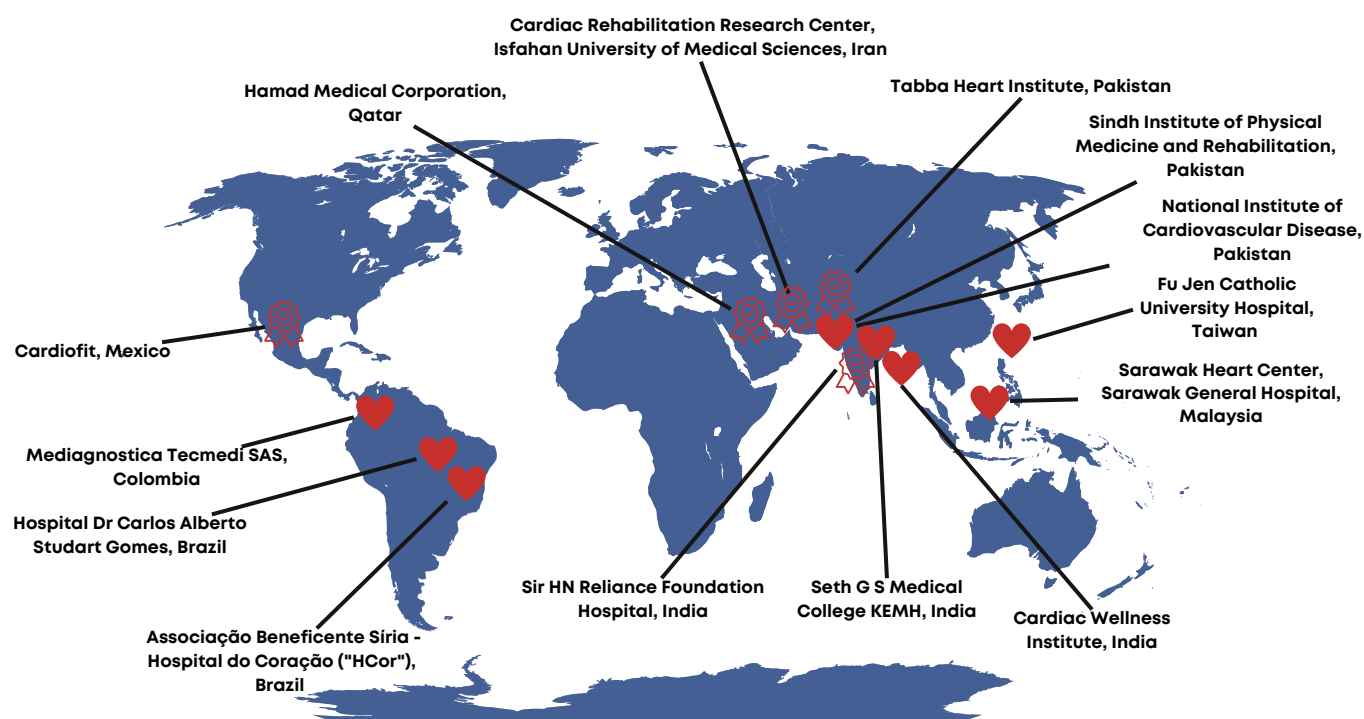
### Publication Policy:

All participating programs have access to their own data from inception, and indeed many have already accessed and used it. To date, no access requests for all site data have been received by the sub-committee, but we expect this will change given the nice maturation of the ICRR. Documents and processes are in place to consider requests in a fair and transparent manner.

[https://globalcardiacrehab.com/resources/Documents/ICRR\\_Data%20Access%20Dissemination%20Policy\\_v3-3.pdf](https://globalcardiacrehab.com/resources/Documents/ICRR_Data%20Access%20Dissemination%20Policy_v3-3.pdf)



# 14 PARTICIPATING CENTERS



ICCPR-certified sites



Participating sites

# PROGRAM CHARACTERISTICS

from the Program Survey sites complete  
before joining the registry, N=11

	n (%) or mean $\pm$ SD
<b>Type of Institution*</b>	
Referral / tertiary / academic centre	9 (81.8)
Private hospital	3 (27.3)
Outside of a hospital	2 (18.2)
<b>Funding for Program*</b>	
Patient	8 (72.7)
Government	4 (36.4)
Other	2 (18.2)
<b>Disciplines on CR Team*</b>	
Physiotherapist	10 (90.9)
Nurse	9 (81.8)
Administrative assistant	9 (81.9)
Any physician	4 (36.4)
Any other type of exercise specialist	4 (36.4)
Other	2 (18.2)
<b>Core Components Offered*†</b>	
Patient education	11 (100)
Prescription / titration of cardiac medications	11 (100)
Resistance training	11 (100)
Nutrition counselling	10 (90.9)
Tobacco cessation sessions/ intervention	10 (90.9)
Stress management / relaxation	10 (90.9)
Program duration (weeks)	8.11 $\pm$ 3.1
Remote delivery available	9 (81.8)
New patients served per month	11.11 $\pm$ 8.1

SD, standard deviation; ICRR, International Cardiac Rehabilitation Registry

\*more than one response could apply to each centre

†Note: participating centres must offer initial assessment and structured, aerobic exercise (supervised or unsupervised) hence they are not listed. They also must offer at least one other component.

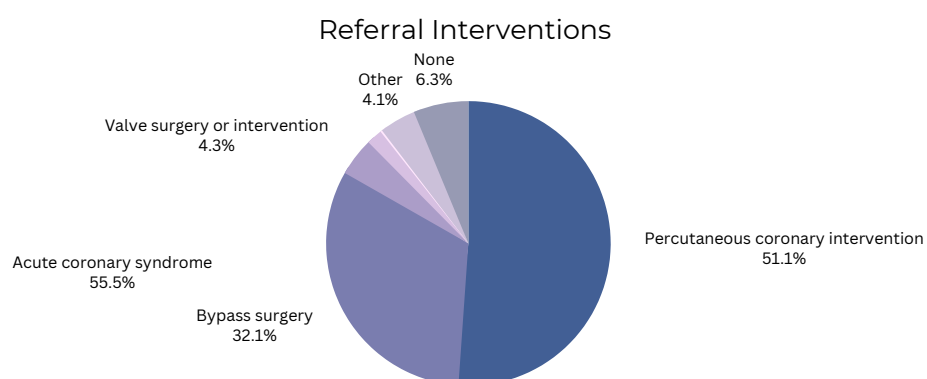
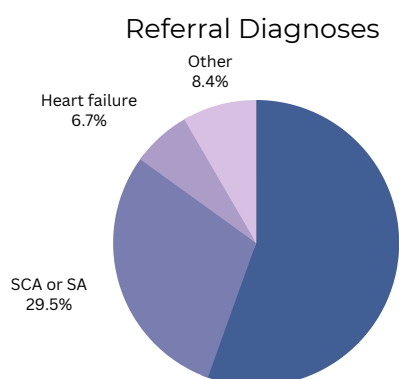
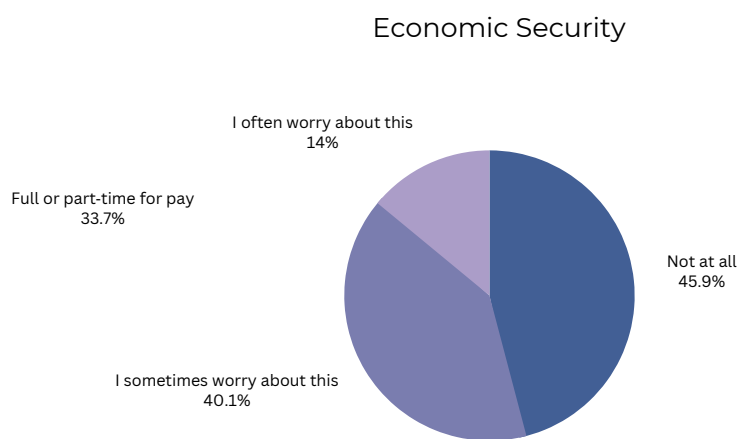
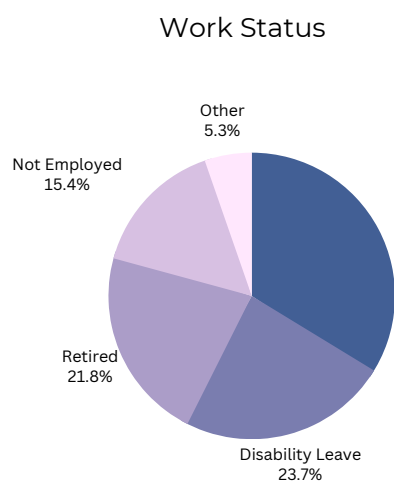
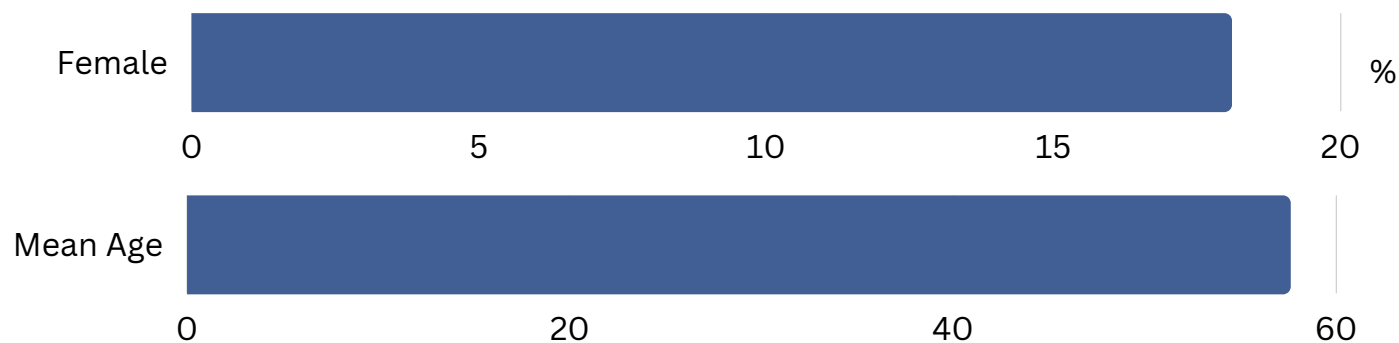
Data downloaded on October 3rd, 2022

# PATIENT CHARACTERISTICS

Please refer to Appendix Table 1 for more details.

**954** Patients in the Registry  
This number represents the total number of patients that have been entered in the registry across all sites.

**848** Patients with Post-Program Data  
This number represents the total number of patients that have any post-program data entered in the registry across all sites.



# CR SITE KUDOS

**It has been a wonderful year since we started operating the registry! We are most grateful to report that based on your contributions since inception, we have 14 sites on board from all corners of the globe, who have entered approximately 1300 patients.**

**I would like to extend a warm welcome to our newest sites: Sindh Institute of Physical Medicine and Rehabilitation, Pakistan; National Institute of Cardiovascular Disease Pakistan, and Hospital Dr. Carlos Alberto Studart Gomes, Brazil. There are many others working on approvals.**



## OUR SITES MEASURE UP!

While sites have different volumes and have joined the registry at different times, we would like to thank and recognize our sites.

Thanks to the Tabbah Heart institute, Pakistan for entering the most data to date. We are also thankful to our Mexican, Iranian and Malaysian sites for highest data entry completeness post-program.

In terms of program performance, here are some really encouraging findings:

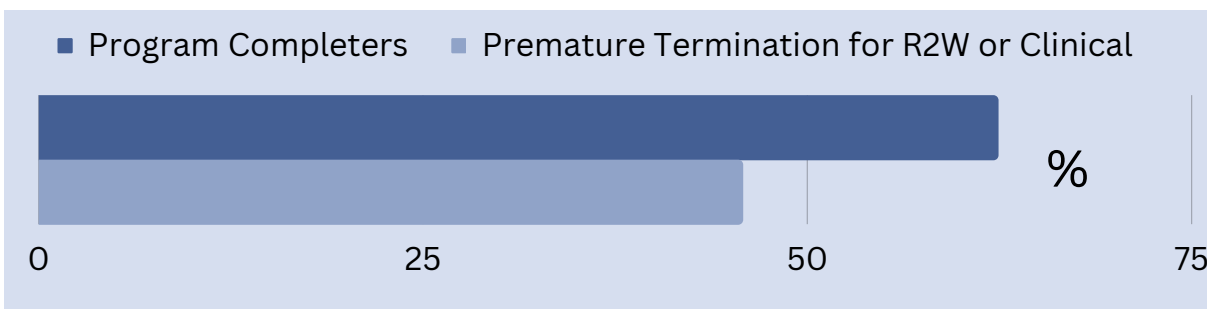
- Patients have an average increase of ~110 minutes of physical activity per week from pre to post-program (Iranian & Pakistan site leading the way!)
- Patients have an average increase of 2/10 in quality of life from pre to post-program (Colombian and Indian sites leading the way!)
- Patients are eating approximately 1 more servings of fruit and vegetables per day from pre to post-program (India site leading the way!)
- 80% of patients know what to do if they have chest pain by post-program (Mexican, Colombian, Malaysian, Indian sites are leading the way!)
- 75% of patients know their cholesterol and how to control it by post-program (Mexican, Colombian and Malaysian sites leading the way!)
- Medication adherence is on average 4.8/5 in patients who have medication coverage post-program (Iran, Pakistan and Malaysia sites leading the way!)

So wonderful for patients of ICRR-participating programs.

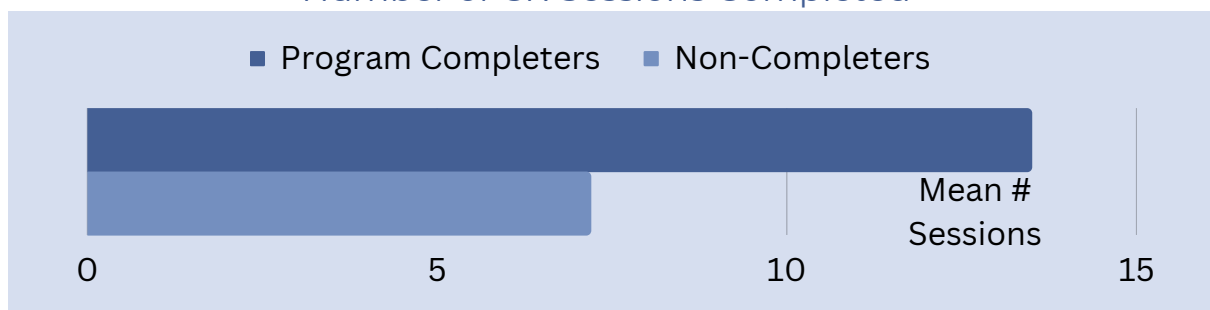
# ICRR DEMONSTRATES CR PROGRAM QUALITY

Please refer to the Appendix Table 2 for outcome data, but below are some highlights to show that ...  
ICRR sites Measure Up!

Program Completers & Premature Termination



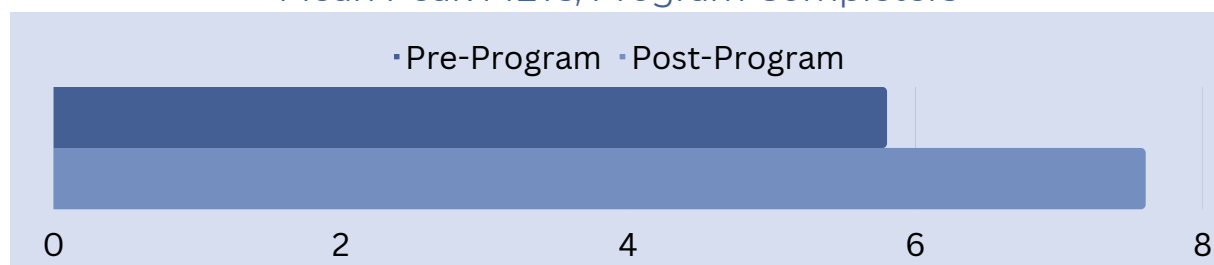
Number of CR Sessions Completed



There were significant improvements in work status, functional capacity, quality of life, physical activity, diet, as well as reductions in tobacco use, body mass index, blood pressure, and depressive symptoms from pre to post-program among completers, with a trend for lower lipids.

Post-program, completers had significantly better work status, functional capacity (see figure below), medication adherence, physical activity levels, diet, as well as lower tobacco use than non-completers, with a trend towards lower depressive symptoms.

Mean Peak METs, Program Completers



# ICCPR PROGRAM CERTIFICATION STEERING COMMITTEE

Governance body for development, implementation and conduct of the program certification initiative, under the auspices of ICCPR Executive.

## Members

Refer to map on page 7 to see the global and discipline representation of our members



ICCPR's program certification scheme recognizes CR programs in low-resource settings who meet a minimum quality standard with regard to program structure, processes and patient outcomes. ICRR-participating programs have the option of pursuing ICCPR Program Certification.

Certified programs must meet 70% of 13 quality standards, including 3 mandatory ones.

Certification consideration involves analysis of program survey and registry data. Eligible programs are then invited for a two-hour virtual site assessment, to demonstrate their ability to meet the quality standards. Successful programs are certified for three full calendar years.

Learn more, and apply here: <https://globalcardiacrehab.com/Program-Certification>

In the first year, five sites have received certification  
(see also map):



# KNOWLEDGE TRANSLATION

Through the registry, there have been some early publications and presentations.

Abukhadajah HJ, Turk-Adawi KI, Dewart N, Grace SL. Qualitative study measuring the usability of the International Cardiac Rehabilitation Registry. *BMJ Open*. 2022 1;12(8):e064255.

Chowdhury MI, Turk-Adawi K, Babu AS, de Melo Ghisi GL, Seron P, Yeo TJ, Uddin J, Heine M, Saldivia MG, Kouidi E, Sadeghi M. Development of the international cardiac rehabilitation registry including variable selection and definition process. *Global Heart*. 2022;17(1).

Grace, S.L., Ahmad, S., Sadeghi, M., Papasavvas, T., Hashmi, F., Ghisi, G.L.M., Vargas, J.A.L., Alhashemi, M., & Turk-Adawi, K. (under review). Pilot testing of the International Council of Cardiovascular Prevention and Rehabilitation's Registry (ICRR).

## CONFERENCES:

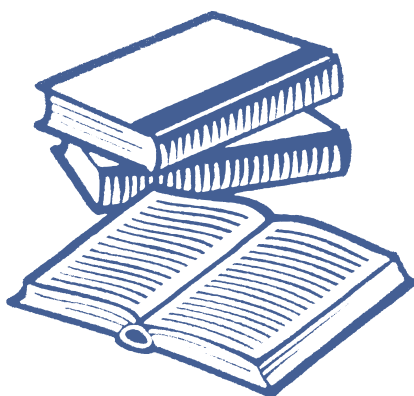
Chowdhury, M., Turk-Adawi, K., Abukhadija, H., & Grace S.L. (2020). Development of the international cardiac rehabilitation registry data dictionary using a delphi process. *Canadian Association of Cardiovascular Prevention and Rehabilitation - Canadian Cardiovascular Congress*. Edmonton, Canada. October. *JCRP*;40:E52.

Ghisi, G.L.M, Back, M, Hashmi, F, Grace, S.L. (2022). Cardiac rehabilitation registries across the globe. *AACVPR Annual Conference*. Florida, USA. September.

Grace, S.L., Lopez-Jimenez, F. (2022). ICCPR's new cardiac rehabilitation registry. *Brazilian Society of Cardiology / World Congress of Cardiology*. Rio de Janeiro, Brazil. October.

Turk-Adawi, K, Abukhadija, H, Grace S.L. (2022). Usability testing of the international cardiac rehabilitation registry. *Canadian Association of Cardiovascular Prevention and Rehabilitation Conference*. [virtual] June.

Turk-Adawi, K, Elashie, S, Hashmi, F, Papasavvas, T, Sadeghi, M, Ghisi, G.M.G., Al-Hashemi, M., & Grace, S.L. (2022). Feasibility of the International Cardiac Rehabilitation Registry. *9th Asian Preventive Cardiology & Cardiac Rehabilitation Conference (APCCRC)*. November. Hong Kong



# LOOKING FORWARD



- 1 Approved data quality audit process to be initiated
- 2 Quality improvement activities
- 3 Hope to get our first data access requests
- 4 Early programs starting annual assessments

## SOME QUOTES FROM PARTICIPATING SITES THAT SHOW HOW PARTICIPATING IN THE REGISTRY HELPS THEM IMPROVE THEIR QUALITY

“... to improve our outcome, we do download [the dashboards] every month”

“That's, you know, putting us onto that track of pushing for certain improvements like patient educaETon.”

- ICRR Site Data Steward



# JOIN THE ICRR

Interested sites can join by completing the program survey on the following ICRR page:  
[https://globalcardiacrehab.com/ICRR\\_sites](https://globalcardiacrehab.com/ICRR_sites)

## Benefits of Joining the Registry

1. Benchmarking
2. Lay summary for patients
3. Exporting your own data
4. Program recognition and potential certification
5. Research involvement opportunities

**What participating sites have to say about the benefits of being in the ICRR:**

"[We hadn't measured] adherence to medication, the [social] support of the patient ... [now measuring that] did help us to help patients get comfortable with their life"

- ICRR Site Data Steward

**The value of the patient lay summary:**

"They could evaluate their health condition and they were very satisfied about that."

"It really benefits the patient to know their progress, to have a documentation of their progress, in layman's terms."

- ICRR Site Data Steward





*We thank you for your continued support  
in our efforts to improve cardiac  
rehabilitation, globally.*

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## CONTACT

### Social Media



[@iccpr\\_crhc](https://www.instagram.com/iccpr_crhc)



[LinkedIn](https://www.linkedin.com/company/iccpr)



[@ICCPR\\_GlobalCR](https://twitter.com/ICCPR_GlobalCR)



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[iccpr.icrr@gmail.com](mailto:iccpr.icrr@gmail.com)

Table 1: Pre-program characteristics of participants entered in the International Cardiac Rehabilitation Registry, N=954

	n (%) or mean $\pm$ SD
<i>Sociodemographic</i>	
Sex (n, % female)	210 (18.1)
Age (years)	57.6 $\pm$ 11.6
Education (years)	13.5 $\pm$ 5.6
Work Status	
Full or part-time for pay (includes self-employment)	308 (32.3)
Disability (sick leave) or modified duties at work	217 (22.7)
Retired	199 (20.9)
Not employed	141 (14.8)
Other	49 (5.1)
Worry about having enough money to meet basic needs, including health and care	
Not at all	422 (44.2)
Sometimes	368 (38.6)
Often	129 (13.5)
Pay for heart pills or medicines out-of-pocket (n, % yes)	747 (78.3)
<i>Clinical</i>	
Referral Diagnoses*	
Acute coronary syndrome	432 (51.6)
Stable coronary artery disease or stable angina	262 (27.5)
Heart failure	59 (6.2)
Other cardiac	74 (7.8)
Referral Interventions*	
Percutaneous coronary intervention	460 (48.2)
Coronary artery bypass surgery	289 (30.3)
Valve surgery or intervention	39 (4.1)
Rhythm device	16 (1.7)
Ablation	2 (0.2)
Other	37 (3.9)
None	56 (5.9)

<b>Risk Factors</b>	
LDL (mmol/L)	4.3 ± 2.4
BMI (kg/m <sup>2</sup> )	27.8 ± 4.8
SBP (mmHg)	122.1 ± 15.6
DBP (mmHg)	73.5 ± 9.8
<b>Comorbidities*</b>	
Diabetes	125 (20.9)
Musculoskeletal issues	18 (3.0)
Lung disease	4 (0.4)
Cancer	4 (0.4)
Peripheral vascular disease / claudication	4 (0.4)
Stroke / transient ischemic attack	3 (0.3)
Cognitive issues	1 (0.1)
<b>Heart-Health Behaviors</b>	
Peak METs	4.8 (3.1)
Physical activity (minutes / week at least moderate intensity)	114.5 (109.1)
Fruit and vegetable intake (servings / day)	3.2 (1.7)
<b>Tobacco Use</b>	
Never	526 (55.1)
Current	141 (14.8)
Former	247 (25.9)
Medication adherence (/5)	1.7 ± 1.0
<b>Psychosocial</b>	
Quality of Life (/10)	5.8 ± 1.3
Social Support (/5)	1.8 ± 0.9
Depressive symptoms (PHQ-2)	1.4 ± 1.5
Positive screen (≥3)	117 (10.6)

CRT: Cardiac resynchronization therapy; ICD: Implantable cardioverter-defibrillator; LDL: Low-density lipoprotein; BMI: Body mass index; SBP: Systolic blood pressure; DBP: Diastolic blood pressure; METs: Metabolic equivalent of task; PHQ-2: Patient Health Questionnaire-2

Note: higher scores are better for medication adherence and quality of life, whereas lower scores are better for depressive symptoms and social support.

\*select all that apply.

Table 2: Retained Participant's Outcomes, N=848||

	Pre-Program		Post-Program		P for change in completers from pre to post	P for difference by completion status at post
Outcome	Program Completers	Non-Completers	Program Completers	Non-Completers		
Work Status					<.001	<.001
Full or part-time	238 (47.5%)	22 (13.2%)	243 (47.2%)	56 (18.2%)		
Disability or modified duties	83 (16.6%)	63 (37.7%)	88 (17.1%)	102 (33.2%)		
Retired	98 (19.6%)	32 (19.2%)	102 (19.9%)	67 (21.8%)		
Not employed	55 (11.0%)	38 (22.8%)	55 (10.7%)	61 (19.9%)		
Other	27 (5.4%)	12 (7.2%)	27 (5.2%)	21 (6.8%)		
Risk Factors						
LDL (mmol/L)	4.5±1.9	4.4±1.7	4.3±2.0	4.7±3.0	.07	*
BMI (kg/m2)	27.4±4.7	27.1±3.9	27.1±4.6	26.3±4.4	<.001	.25
SBP (mmHg)	121.5±16.3	120.7±12.9	119.7±16.6	120.9±13.4	<.01	.45
DBP (mmHg)	73.4±10.4	71.1±8.7	70.8±9.2	70.5±7.9	<.001	.73

<b>Heart-Health Behaviors</b>						
<b>Peak METs</b>	5.9±3.2	2.6±2.4	7.2±3.8	5.1±0.7	<.001	<.001
<b>Physical activity (minutes / week at least moderate intensity)</b>	120.0±113.7	100.8±95.3	245.3±139.2	193.7±98.8	<.001	<.001
<b>Fruit and vegetable intake (servings / day)</b>	3.8±1.7	3.2±1.3	4.8±1.4	4.3±1.2	<.001	<.001
<b>Tobacco Use</b>					<.001	.001
<b>Never</b>	293 (56.0%)	93 (53.8%)	293 (60.4%)	93 (56.1%)		
<b>Current</b>	50 (9.6%)	42 (24.3%)	40 (7.6%)	30 (17.3%)		
<b>Former</b>	166 (31.7%)	35 (20.2%)	167 (31.9%)	46 (26.6%)		
<b>Medication adherence‡ (/5)</b>	1.3±0.9	2.5±1.2	1.3±0.6	1.1±0.4	.14	<.01
<b>Psychosocial</b>						
<b>Quality of Life (/10)</b>	5.7±1.4	5.8±1.1	7.5±1.3	7.4±1.1	<.001	.24
<b>Depressive symptoms (PHQ-2)</b>	1.3±1.4	1.5±1.7	1.3±1.4	1.5±1.7	<.001	.06

Note: n (%) or mean ± standard deviation shown

LDL: Low-density lipoprotein; BMI: Body mass index; SBP: Systolic blood pressure; DBP: Diastolic blood pressure; METS: Metabolic equivalent of task; PHQ-2: Patient Health Questionnaire-2

Note: higher scores are better for medication adherence and quality of life, whereas lower scores are better for depressive symptoms.

\*cell sizes too small for inferential testing.

||varies by outcome due to missing data.

‡in those who have medication coverage only.