

Domain One: Defining pediatric cardiac rehabilitation and identifying exercise training elements necessary to maximize physical fitness in children and adolescents with congenital heart disease.

Please complete the survey for "Domain One" below based on your experience and knowledge when working with children and adolescents with CHD and exercise.

Remember

- There is a button on the bottom of this survey page labeled "Save and Return." If you need to take a break before completing the survey you may use this option. When you click the "Save and Return" button you will be able to save your responses, make changes and go back to the survey.
- When you are finished with this survey, it is important to remember to hit the 'submit' button at the end of the survey to ensure your completed questionnaire is saved.
- Once responses are submitted, you will no longer be able to edit or change your responses.

Thank you!

Introduction to Survey #1

Pediatric cardiac rehabilitation can improve cardiovascular fitness for children with a variety of congenital heart defects (CHD). Yet, there are no formal guidelines regarding the optimal design and implementation of a pediatric cardiac rehabilitation program. The purpose of this survey is to engage experts in congenital heart disease and pediatric exercise physiology regarding specific content necessary for a pediatric cardiac rehabilitation curriculum for children and adolescents with congenital heart disease.

This first survey is intended to define the BROAD elements that should be included in a pediatric cardiac rehabilitation curriculum. The four domains that will be explored are 1) exercise training elements, 2) education topics, 3) outcome metrics, and 4) self-confidence strategies. The results from this survey will then be further explored in subsequent surveys based on your responses. All responses will remain confidential and accessible only by the study team.

Survey instructions:

- Please answer the questions based on your experience and knowledge when working with children and adolescents with CHD and exercise.
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- When you are finished with that particular survey, it is important to remember to hit the 'submit' button at the end of each survey to ensure your completed questionnaire is saved. You will need to do this for each domain.
- Once responses are submitted, you will no longer be able to edit or change your responses.

Domain One: Defining pediatric cardiac rehabilitation and identifying exercise training elements necessary to maximize physical fitness in children and adolescents with congenital heart disease.

1) To what extent do you agree with this definition for a pediatric cardiac rehabilitation program for the CHD population:

"Pediatric cardiac rehabilitation is a medically supervised program designed to optimize a congenital cardiac patient's cardiovascular function, self-confidence, nutrition, and habits for leading heart healthy lives. This includes physician prescribed, developmentally appropriate exercise and physical activity goals, patient and family education, psychosocial assessment, nutrition assessment, and outcomes assessment."

- Strongly agree
- Agree
- Neutral
- Disagree
- Strongly disagree

Question 1 - Please let me know what you would change or add to this definition:

2) Ideally, how many medically supervised structured exercise sessions should CHD patients attend during the entire outpatient pediatric rehabilitation program? Please feel free to identify different ranges and/or discuss the reasoning for your response by selecting "other".

- 1-5
- 6-10
- 11-15
- 16-20
- 21-25
- 26-30
- 31-36
- Other

Please identify different ranges and/or discuss the reasoning for your response:

3) How many days a week should CHD patients attend a medically supervised structured exercise program? Please feel free to identify other options and/or discuss the reasoning for your response by selecting "other".

- 1
- 2
- 3
- 4
- 5
- Other

Please identify other options and/or discuss the reasoning for your response:

4) How many days a week should CHD patients exercise in a home-based exercise program to complement the supervised program? Please feel free to identify additional days and/or discuss the reasoning for your response by selecting "other".

- 1
- 2
- 3
- 4
- 5
- Other

Please identify additional days and/or discuss the reasoning for your response:

5) What is the ideal AVERAGE targeted heart rate training intensity range for CHD patients to aerobically train at in a medically supervised structured exercise program? Please feel free to identify different ranges and/or discuss the reasoning for your response by selecting "other".

- 50-65%
- 60-70%
- 65-75%
- 70-80%
- 75-85%
- Other

Please identify different ranges and/or discuss the reasoning for your response:

6) What is the ideal mix of Moderate Intensity Continuous Training (MICT 50-85%HRmax) and High Intensity Interval Training (HIIT >85%HRmax) for a medically supervised structured exercise program? Please feel free to identify a different mix of training and/or discuss the reasoning for your response by selecting "other".

- MICT 100%, HIIT 0%
 MICT 70%, HIIT 30%
 MICT 50%, HIIT 50%
 MICT 30%, HIIT 70%
 MICT 0%, HIIT 100%
 Other

Please identify a different mix of training and/or discuss the reasoning for your response:

7) How many minutes of each supervised session should be spent exercising? Please feel free to identify different range by selecting "other".

- 10-20
 20-30
 30-40
 40-50
 50-60
 Other

Please identify different range:

8) Please specify the ideal mix of aerobic, strength and flexibility exercise during each supervised training session (should add up to 100%).

Example: Aerobic 50%, Strength 25% and Flexibility 25% total = 100%

Aerobic:

(% training)

Strength:

(% training)

Flexibility:

(% training)

Total:

(% training)

Your Total is larger than 100%, please go back and edit your percentages

9) What other exercise training principles are critical to include in an outpatient supervised pediatric cardiac rehabilitation curriculum?

Domain Two: Identifying education topics that set heart healthy habits for life in children and adolescents with congenital heart disease.

Please complete the survey below for "Domain Two" based on your experience and knowledge when working with children and adolescents with CHD and exercise.

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Thank you!

1) How important is the inclusion of heart healthy education in a pediatric cardiac rehabilitation program?

- Very important
 Important
 Moderately important
 Slightly important
 Not important

2) How important is the inclusion of family (parent, caregiver, siblings) in receiving heart healthy education in a pediatric cardiac rehabilitation program?

- Very important
 Important
 Moderately important
 Slightly important
 Not important

3) Please indicate how important you think it is to discuss each heart healthy education topic for inclusion in a pediatric cardiac rehabilitation program.

	Very important	Important	Moderately important	Slightly important	Not important
Physical activity counseling	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Nutrition counseling	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Weight management	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mindset/confidence/anxiety management	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lipid management	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Blood pressure management	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tobacco	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lifestyle topics (i.e. sleep, limiting sedentary time)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

3a What other education topics may be critical to include in a pediatric cardiac rehabilitation program?

4) How should patient and/or family education be received in a pediatric cardiac rehabilitation program? Please rank the following order from most (1) to least (3) preferred method by selecting the appropriate number.

Please be sure to only use each number once when ranking.

Individual patient session 1
 2
 3

Patient and family session 1
 2
 3

Group session 1
 2
 3

5) How should patient and/or family education be delivered in a pediatric cardiac rehabilitation program? Please rank the following order from most (1) to least (5) preferred method by selecting the appropriate number.

Please be sure to only use each number once when ranking.

Online 1
 2
 3
 4
 5

In person 1
 2
 3
 4
 5

In print (handouts) 1
 2
 3
 4
 5

Video conferencing 1
 2
 3
 4
 5

Via an app 1
 2
 3
 4
 5

Domain Three: Identifying patient outcome measures to include in a pediatric cardiac rehabilitation curriculum for children and adolescents with congenital heart disease.

Please complete the survey for "Domain Three" below based on your experience and knowledge when working with children and adolescents with CHD and exercise.

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Thank you!

Please rank the importance of each category for measuring and assessing patient outcomes for inclusion in a pediatric cardiac rehabilitation curriculum.

	Very important	Important	Moderately important	Slightly important	Not important
1) Peak VO ₂ capacity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2) VO ₂ capacity at ventilatory anaerobic threshold (VAT)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3) Heart Rate at VAT	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4) Heart rate (rest, submaximal, maximal)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5) Blood pressure (rest, exercise, recovery)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6) ECG telemetry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7) Peak METs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8) Total physical activity minutes per week	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9) Muscle strength	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10) Flexibility	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11) Lipid levels	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12) Blood glucose levels	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13) Anthropometric measures (height, weight, BMI, body composition)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14) Bone mineral density tests	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15) Psychosocial questionnaires (mood and cognitive)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16)					

- | | | | | | |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Quality of life questionnaires | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 17) Self-efficacy/confidence questionnaires | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 18) Physical Activity Questionnaires | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
-

19) What other measurable patient outcomes do you think are critical to include in a pediatric cardiac rehabilitation program for CHD patients?

- 20) How important is the inclusion of baseline assessments for patient outcomes prior to the start of cardiac rehabilitation?
- Very important
 - Important
 - Moderately important
 - Slightly important
 - Not important
-

- 21) How important is the inclusion of ongoing assessments for patient outcomes during cardiac rehabilitation?
- Very important
 - Important
 - Moderately important
 - Slightly important
 - Not important
-

22) How frequently should the ongoing assessments occur for patients actively enrolled in cardiac rehabilitation? (i.e. every 10 days, 30 days, 45 days, etc.)

- 23) How important is the inclusion of discharge assessments for patient outcomes after participating in cardiac rehabilitation?
- Very important
 - Important
 - Moderately important
 - Slightly important
 - Not important

Domain Four: Identifying whether promoting self-confidence is important to include in a pediatric cardiac rehabilitation program.

This is the final domain/survey for round one in this e-Delphi process.

Please complete based on your experience and knowledge when working with children and adolescents with CHD and exercise.

Thank you!

Participation in regular physical activity yields not only cardiovascular benefits, but a multitude of social and emotional benefits as well. Some believe regular physical activity and exercise can be beneficial towards increasing self-confidence, which is defined as trust in one's own ability or belief that one can successfully face day to day challenges and demands. How to best develop self-confidence has not been well documented in the literature or formally addressed in a pediatric cardiac rehabilitation program. Gathering opinions in this understudied area could provide insight toward the development of a pediatric cardiac rehabilitation curriculum.

1) How important is it to understand the degree of self-confidence in a child or adolescent with CHD in helping to establish successful exercise and heart healthy habits? Please feel free to discuss your reasoning for your response in the comment box below.

- Very important
 Important
 Moderately important
 Slightly important
 Not important
-

Question 1 Comments:

2) How important is it to develop strategies to promote self-confidence as part of a pediatric cardiac rehabilitation curriculum? Please feel free to discuss your reasoning for your response in the comment box below.

- Very important
 Important
 Moderately important
 Slightly important
 Not important
-

Question 2 Comments:

3) Do you include self-confidence building techniques in your exercise program?

- Yes
 No
-

If yes, what are these techniques/strategies:

What ideas might you have to promote self-confidence for this patient population?

OVERALL QUESTION

1) What other components that were not addressed in the domains above are critical to include in a pediatric cardiac rehabilitation curriculum?
