



# APPROACH-IS INFOFLASH November 2017

"APPROACH-IS is a real game changer!"

Dr Jamil Aboulhosn  
University of California  
in Los Angeles (UCLA)

...UPDATE...

- To date, 9 articles on APPROACH-IS data have been published in international peer-reviewed journals
- Thirteen presentations at national and international conferences have been given
- More manuscripts are in the pipeline

## January 2015



Assessment of Patterns of Patient-Reported Outcomes in Adults with Congenital Heart Disease – International Study (APPROACH-IS): Rationale, design, and methods<sup>1</sup>

Silke Apers<sup>1</sup>, Adrienne H. Kovacs<sup>2</sup>, Koen Luyckx<sup>3</sup>, Luis Alday<sup>4</sup>, Malin Berghammer<sup>5</sup>, Werner Budts<sup>6</sup>, Edward Callus<sup>7</sup>, Mayarane Caruana<sup>8</sup>, Shanthi Chidambaram<sup>9</sup>, Stephen C. Cook<sup>10</sup>, Mikael Dellborg<sup>11</sup>, Juniko Enomoto<sup>12</sup>, Karinne Erikson<sup>13</sup>, Susan M. Fernandes<sup>14</sup>, Jamie L. Jackson<sup>15</sup>, Bengt Johansson<sup>16</sup>, Paul Khairy<sup>17</sup>, Shelby Kutty<sup>18</sup>, Samuel Menahem<sup>19</sup>, Gwen Krompel<sup>20</sup>, Maayke A. Slaman<sup>21</sup>, Alexandra South<sup>22</sup>, Corinna Thomet<sup>23</sup>, Gruschen Veldman<sup>24</sup>, Joo-Kou Wang<sup>25</sup>, Kamila White<sup>26</sup>, Philip Moons<sup>27,28</sup>

<https://www.ncbi.nlm.nih.gov/pubmed/25464481>

## May 2016



Quality of Life of Adults With Congenital Heart Disease in 15 Countries  
Evaluating Country-Specific Characteristics

Silke Apers, PhD<sup>1</sup>, Adrienne H. Kovacs, PhD<sup>2</sup>, Koen Luyckx, PhD<sup>3</sup>, Corinna Thomet, MSc<sup>4</sup>, Werner Budts, MD, PhD<sup>5</sup>, Juniko Enomoto, PhD<sup>6</sup>, Maayke A. Slaman, MD<sup>7</sup>, Joo-Kou Wang, MD, PhD<sup>8</sup>, Jamie L. Jackson, PhD<sup>9</sup>, Paul Khairy, MD, PhD<sup>10</sup>, Stephen C. Cook, MD<sup>11</sup>, Shanthi Chidambaram, MD<sup>12</sup>, Luis Alday, MD<sup>13</sup>, Karinne Erikson, MSc<sup>14</sup>, Mikael Dellborg, MD, PhD<sup>15</sup>, Malin Berghammer, PhD<sup>16</sup>, Eva Mattsson, MD, PhD<sup>17</sup>, Andrew S. Mackie, MD<sup>18</sup>, Samuel Menahem, MD<sup>19</sup>, Mayarane Caruana, MD<sup>20</sup>, Gruschen Veldman, MD<sup>21</sup>, Alexandra South, MD<sup>22</sup>, Anita W. Booth, MD<sup>23</sup>, Kamila White, PhD<sup>24</sup>, Edward Callus, PhD<sup>25</sup>, Shelby Kutty, MD<sup>26</sup>, Stefan Fleuss, PhD<sup>27</sup>, Philip Moons, PhD<sup>28</sup>, on behalf of the APPROACH-IS consortium and ISACHD

<https://www.ncbi.nlm.nih.gov/pubmed/27173035>

## April 2017



Original Article

Comparison of participants and non-participants in patient-reported outcome surveys: the case of Assessment of Patterns of Patient-Reported Outcomes in Adults with Congenital Heart Disease – International Study

Malin C. Berghammer<sup>1,2,3</sup>, Eva Mattsson<sup>4</sup>, Bengt Johansson<sup>5</sup>, Philip Moons<sup>2,6,7</sup>, Mikael Dellborg<sup>1,2,8</sup>

<https://www.ncbi.nlm.nih.gov/pubmed/27167242>

## June 2017



Red Flags for Maltese Adults with Congenital Heart Disease: Poorer Dental Care and Less Sports Participation Compared to Other European Patients—An APPROACH-IS Substudy

Mayarane Caruana<sup>1</sup>, Silke Apers<sup>2,3</sup>, Adrienne H. Kovacs<sup>4</sup>, Koen Luyckx<sup>5</sup>, Corinna Thomet<sup>6</sup>, Werner Budts<sup>7</sup>, Maayke Slaman<sup>8</sup>, Karinne Erikson<sup>9</sup>, Mikael Dellborg<sup>10,11</sup>, Malin Berghammer<sup>12,13</sup>, Bengt Johansson<sup>14</sup>, Alexandra South<sup>15</sup>, Edward Callus<sup>16</sup>, Philip Moons<sup>17,18</sup>, Victor Green<sup>19</sup>, on behalf of the APPROACH-IS consortium and the International Society for Adult Congenital Heart Disease (ISACHD)

<https://www.ncbi.nlm.nih.gov/pubmed/28341902>

## September 2017



Patient reported outcomes are associated with physical activity level in adults with congenital heart disease

Anika Bay<sup>1,2,3</sup>, Mikael Dellborg<sup>4,5</sup>, Malin Berghammer<sup>6,7</sup>, Camilla Sandberg<sup>8,9</sup>, Gunnar Engström<sup>10,11</sup>, Philip Moons<sup>12,13</sup>, Bengt Johansson<sup>14</sup>

<https://www.ncbi.nlm.nih.gov/pubmed/28747022>

## October 2017



Original Article

Determinants of quality of life in adults with CHD: an Australian cohort\*

Sarah L. Eaton<sup>1,2</sup>, Qifeng Wang<sup>3</sup>, Samuel Menahem<sup>4</sup>

<https://www.ncbi.nlm.nih.gov/pubmed/28651679>

## October 2017



Illness perceptions in adult congenital heart disease: A multi-center international study<sup>1</sup>

Jessica Ranaivosoa<sup>1,2,3</sup>, Silke Apers<sup>4</sup>, Adrienne H. Kovacs<sup>5</sup>, Philip Moons<sup>6,7</sup>, Corinna Thomet<sup>8</sup>, Werner Budts<sup>9,10</sup>, Juniko Enomoto<sup>11</sup>, Maayke A. Slaman<sup>12</sup>, Joo-Kou Wang<sup>13</sup>, Jamie L. Jackson<sup>14</sup>, Paul Khairy<sup>15</sup>, Stephen C. Cook<sup>16</sup>, Rajwan Subramanyam<sup>17</sup>, Luis Alday<sup>18</sup>, Karinne Erikson<sup>19</sup>, Mikael Dellborg<sup>20,21</sup>, Malin Berghammer<sup>22</sup>, Bengt Johansson<sup>23</sup>, Gwen Krompel<sup>24</sup>, Samuel Menahem<sup>25</sup>, Mayarane Caruana<sup>26</sup>, Gruschen Veldman<sup>27</sup>, Alexandra South<sup>28</sup>, Susan M. Fernandes<sup>29</sup>, Kamila White<sup>30</sup>, Edward Callus<sup>31</sup>, Shelby Kutty<sup>32</sup>, Koen Luyckx<sup>33</sup>, on behalf of the APPROACH-IS consortium and the International Society for Adult Congenital Heart Disease (ISACHD)

<https://www.ncbi.nlm.nih.gov/pubmed/28669511>

## November 2017

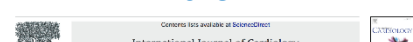


Regional variation in quality of life in patients with a Fontan circulation: A multinational perspective

Nicholas D. Fogelman, MS<sup>1,2</sup>, Silke Apers, PhD<sup>3,4</sup>, Philip Moons, PhD, RN<sup>5,6</sup>, Stacy Morrison, PhD<sup>7</sup>, Samuel C. Winkler, MD<sup>8</sup>, Martha Tomalia, PhD<sup>9</sup>, Kathy Goerres, MSW<sup>10</sup>, Maayke A. Slaman, MD<sup>11</sup>, Bengt Johansson, MD, PhD<sup>12</sup>, Juniko Enomoto, PhD<sup>13</sup>, Mikael Dellborg, MD, PhD<sup>14</sup>, Chan-Wei Lu, MD, PhD<sup>15</sup>, Rajwan Subramanyam, MD, DM, FRCP, FRCS, FRCR<sup>16</sup>, Koen Luyckx, PhD<sup>17</sup>, Werner Budts, MD, PhD<sup>18</sup>, Jamie L. Jackson, PhD<sup>19</sup>, Adrienne Kovacs, PhD<sup>20</sup>, Alexandra South, MD<sup>21</sup>, Karinne Erikson, MSc<sup>22</sup>, Corinna Thomet, MSc<sup>23</sup>, Malin Berghammer, PhD<sup>24</sup>, Edward Callus, PhD<sup>25</sup>, Susan M. Fernandes, PhD<sup>26</sup>, Mayarane Caruana, MD<sup>27</sup>, Gruschen Veldman, MD, PhD<sup>28</sup>, Andrew S. Mackie, MD<sup>29</sup>, Kamila White, PhD<sup>30</sup>, Paul Khairy, MD, PhD<sup>31</sup>, Shelby Kutty, MD<sup>32</sup>, and Gruschen Veldman, MD, PhD, FRCP<sup>33</sup>, on behalf of the APPROACH-IS consortium, Copenhagen, Colombia, UAE, Fayetteville, KY, Geneva, Belgium, Guelphburg, Iowa, Philadelphia, Sweden, Amsterdam, the Netherlands, China, Japan, Taipei, Taiwan, Czechia, India, Fribourg, Luxembourg, Montreal, Canada, Lyon, France, Oulu, Norway, Bern, Switzerland, Milan, Italy, Singapore, C. R. India, Pittsburgh, PA, Saint Louis, MO, Columbia, SC

<https://www.ncbi.nlm.nih.gov/pubmed/29129255>

## 2018



Patient-reported outcomes in adults with congenital heart disease: Inter-country variation, standard of living and healthcare system factors<sup>1</sup>

Philip Moons<sup>1,2,3,4</sup>, Adrienne H. Kovacs<sup>5,6</sup>, Koen Luyckx<sup>7</sup>, Corinna Thomet<sup>8</sup>, Werner Budts<sup>9,10</sup>, Juniko Enomoto<sup>11</sup>, Maayke A. Slaman<sup>12</sup>, Luis Alday<sup>13</sup>, Karinne Erikson<sup>14</sup>, Mikael Dellborg<sup>15,16</sup>, Malin Berghammer<sup>17</sup>, Bengt Johansson<sup>18</sup>, Andrew S. Mackie<sup>19</sup>, Samuel Menahem<sup>20</sup>, Mayarane Caruana<sup>21</sup>, Gruschen Veldman<sup>22</sup>, Alexandra South<sup>23</sup>, Susan M. Fernandes<sup>24</sup>, Kamila White<sup>25</sup>, Edward Callus<sup>26</sup>, Shelby Kutty<sup>27</sup>, Lecker Van Buick<sup>28</sup>, Silke Apers<sup>29</sup>, on behalf of the APPROACH-IS consortium and the International Society for Adult Congenital Heart Disease (ISACHD)

<https://www.ncbi.nlm.nih.gov/pubmed/29107358>

STAY INFORMED!! VISIT: [www.approach-is.net](http://www.approach-is.net)