Appendix A

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Table 2.4. Literature Synthesis Supplemental Table
TO: Nancy McCabe, RN  
Principal Investigator  
Graduate Nursing

DATE: July 12, 2013

RE: **Expeditied Approval**  
IRB00067006  
Antecedents and Outcomes of Self-Care in Adult Congenital Heart Disease

Thank you for submitting a new application for this protocol. This research is eligible for expedited review under 45 CFR 46.110 and/or 21 CFR 56.110 because it poses minimal risk and fits the regulatory categories F(4, 5, and 7) as set forth in the Federal Register. The Emory IRB reviewed it by expedited process on 7/11/2013 and granted approval effective from **7/11/2013** through **7/10/2014**. Thereafter, continuation of human subjects research activities requires the submission of a renewal application, which must be reviewed and approved by the IRB prior to the expiration date noted above. Please note carefully the following items with respect to this approval:

- Study Protocol, undated, uploaded 6/1/2013
- Consent and Authorization documents:
  - Consent form, version date 7/1/2013
  - HIPAA Authorization form, version date 7/1/2013
  - Revocation letter, version date 7/1/2013
- Study Instruments:
  - Participant Screening and Enrollment form
  - Health Distress form
  - Chronic Disease Self-Efficacy Scales
  - Parental Bonding Instrument
  - Patient Health Questionnaire (PHQ-9)
  - Six Minute Walk Test Score Sheet
  - Personal Health Passport
  - Self-care Index for Adults with Congenital Heart Defects
  - Demographic Survey - Chart Review
  - Demographic Survey
  - Health Resource Use Diary
  - QoL/Health Scales

Any reportable events (e.g., unanticipated problems involving risk to subjects or others, noncompliance, breaches of confidentiality, HIPAA violations, protocol deviations) must be reported to the IRB according to our Policies & Procedures at [www.irb.emory.edu](http://www.irb.emory.edu), immediately,
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Table 2.4. Literature Synthesis Supplemental Table
promptly, or periodically. Be sure to check the reporting guidance and contact us if you have questions. Terms and conditions of sponsors, if any, also apply to reporting.

Before implementing any change to this protocol (including but not limited to sample size, informed consent, and study design), you must submit an amendment request and secure IRB approval.

In future correspondence about this matter, please refer to the IRB file ID, name of the Principal Investigator, and study title. Thank you

Sam Roberts, BA CIP
Senior Research Protocol Analyst
This letter has been digitally signed

CC: Jennings  Staci  MedCardio
    Book    Wendy  MedCardio
    Butler  Javed  MedCardio
    Dunbar  Sandra  Nursing - Main
    Higgins  Melinda  Nursing - Main
    Reilly  Carolyn  Nursing - Main

Emory University
1599 Clifton Road, 5th Floor - Atlanta, Georgia 30322
Tel: 404.712.0720 - Fax: 404.727.1358 - Email: irb@emory.edu - Web: http://www.irb.emory.edu/
An equal opportunity, affirmative action university
Title: Antecedents and Outcomes of Self-care in Adults with Congenital Heart Defects

Principal Investigator: Nancy McCabe, RN, BSN, BA, Nell Hodgson Woodruff School of Nursing, Emory University

Funding Source: National Institute of Nursing Research Predoctoral Grant

Introduction
You are being asked to be in a nursing research study. This form tells you what you need to think about before you agree to be in the study or not. It is entirely your choice. If you decide to take part, you can change your mind later and withdraw from the research study. When filling out study surveys, you can skip any questions that you do not wish to answer. Please read this consent form carefully. If you agree, sign this form, giving your written consent to be in this study.

Before making your decision:
• Please carefully read this form or have it read to you
• Please ask questions about anything that is not clear

You can take a copy of this consent form, to keep. Feel free to take your time thinking about whether you would like to be in this study. By signing this form you will not give up any legal rights. You will also continue to receive the same quality of care by your healthcare provider whether or not you take part in this study.

Study Overview
This study has two main purposes:
1. To understand what helps adults with congenital heart defects to manage their heart condition (self-care).
2. To understand how self-care can improve the health and well-being of adults with congenital heart defects.

Procedures
Everyone in this study will take part in the following activities:
• Complete surveys in an online computer survey or in a paper packet. It is your choice.
• At your next clinic visit, walk as far as you can along a level hallway for 6 minutes.
• Keep track of how often you use the healthcare system (doctor visits, hospitalizations, and emergency room visits,) for 3 months.

The principal investigator is looking for 120 adults with congenital heart defects to be in this study. You and other adults with congenital heart defects have been selected because you attend the Emory Adult Congenital Heart Clinic and qualify for this study. Everyone who qualifies has been mailed a letter of invitation to join the study.

In your invitation letter, you have also received this consent form, a HIPAA authorization form, and a revocation letter. If you decide not to be in this study, contact Nancy McCabe, the principal investigator and discard all of the paperwork you received. We will no longer consider you a potential participant. If you decide to take part in this study after reading this whole form, contact the principal investigator. She will give you a link to fill out the surveys online using a computer. You may also request paper surveys that you can fill out at your next clinic visit. Bring all forms with you to your next clinic visit.
A nurse researcher will meet you at your next clinic visit to collect these forms, sign this consent and HIPAA forms, and conduct a simple walking test. For the walking test, you will walk at a comfortable pace along a level hallway for 6 minutes. You may rest or stop at any time. After your clinic visit, a nurse researcher will contact you by telephone or e-mail (your choice) once a month for 3 months to collect information on how often you used the healthcare system.

**Risks and Discomforts**
There are few risks to you for being in this study. There is a slight chance you might feel stressed or distressed after completing the surveys. One of the surveys is about depression. If your score shows that you have moderate depression, we will tell you and give you information on getting help. If your score shows that you have severe depression, we will tell you and your healthcare provider and also give you information on getting help. On rare occasions during the walking test, participants may feel short of breath or chest pain. The walking test is closely monitored by trained health care personnel and is only done after a short physical exam including taking your blood pressure, heart rate, and discussing your symptoms. You may stop and rest if needed. Also, your heart rate and oxygen levels will be monitored during the test using an oxygen monitor placed on your finger.

**Benefits**
This study is not designed to benefit you directly. This study is designed to learn more about how adults with congenital heart defects manage their heart condition and how that helps improve their health. The study results may be used to help others in the future.

**Compensation**
You will be given a $10 gift card and a free valet parking voucher at your clinic visit. You will get another $10 gift card at the end of the study. We will give you $20 in gift cards and you will receive free parking at your clinic visit if you complete this study.

**Confidentiality**
Certain offices and people other than the researchers may look at study records. Government agencies and Emory employees overseeing proper study conduct may look at your study records. These offices include the Emory Institutional Review Board and the Emory Office of Research Compliance. Study funders may also look at your study records. Emory will keep any research records we create private to the extent we are required to do so by law. A study number rather than your name will be used on study records wherever possible. Your name and other facts that might point to you will not appear when we present this study or publish its results.

**Study Information Will Go Into Medical Record:**
If you are or have ever been an Emory Healthcare patient, you have an Emory Healthcare medical record. If you agree to be in this study, a copy of the consent form and HIPAA form that you sign will be placed in your Emory Healthcare medical record. Emory Healthcare may create study information about you that can help Emory Healthcare take care of you. This includes the results of your walking test. Anyone who has access to your medical record will be able to see the results of your walking test. The confidentiality of this study result will be protected by laws like the HIPAA Privacy Rule. On the other hand, some state and federal laws and rules may not protect the research information from disclosure. Study records can be opened by court order. They may also be produced in response to a subpoena or a request for production of documents.

**Costs**
There are no costs to you associated with this study.
Voluntary Participation and Withdrawal from the Study
You have the right to leave a study at any time without penalty. You may refuse to do any procedures you do not feel comfortable with, or answer any questions that you do not wish to answer. Should you withdraw from the study, you can request that your information not be used by completing the Revocation Letter.

Contact Information
Contact Nancy McCabe at (404) 234-1574 or nmccabe@emory.edu:
• if you have any questions about this study
• if you want to be in this study
• if you have questions, concerns or complaints about this study

Contact the Emory Institutional Review Board at 404-712-0720 or 877-503-9797 or irb@emory.edu:
• if you have questions about your rights as a research participant.
• if you have questions, concerns or complaints about the research.
• You may also let the IRB know about your experience as a research participant through our Research Participant Survey at http://www.surveymonkey.com/s/6ZDMW75.

Written Consent Documentation For Participation
Please, print your name and sign below if you agree to be in this study. By signing this consent form, you will not give up any of your legal rights. We will give you a copy of the signed consent, to keep.

Name of Subject

________________________________________
Signature of Subject

Date
Time

________________________________________
Signature of Person Conducting Informed Consent Discussion

Date
Time
Emory University Research Subject HIPAA Authorization to Use or Disclose Health Information that Identifies You for a Research Study

**Title:** Antecedents and Outcomes of Self-care in Adults with Congenital Heart Defects

**Principal Investigator:** Nancy McCabe, RN, BSN, BA, Nell Hodgson Woodruff School of Nursing, Emory University

**Introduction**
The privacy of your health information is important to us. We call your health information that identifies you, your “protected health information” or “PHI.” To protect your PHI, we will follow federal and state privacy laws, including the Health Insurance Portability and Accountability Act (HIPAA). We refer to all of these laws in this form as the Privacy Rules. This form explains how we will use your PHI for this study.

Please read this form carefully and if you agree with it, sign it at the end.

**Description of Research Study**
This study has two main purposes:

1. To understand what helps adults with congenital heart defects to manage their heart condition (self-care).
2. To understand the relationship between self-care and health outcomes (symptom burden, quality of life, functional health status, and health resource use).

Researchers will gather data from questionnaires and a simple walking test that lasts six minutes.

**PHI That Will Be Used/Disclosed**
The PHI that we may use or disclose (share) for this research study includes:
- Your medical record while being treated at Emory Healthcare, including but not limited to:
  - Cardiology Records
  - Medical history
  - Laboratory/diagnostic tests
  - Updated contact information
  - Hospital and/or Emergency room visits

**Purposes for Which Your PHI Will Be Used**
If you sign this form, you give us your permission to use your PHI for the conduct and oversight of this research study.

**People That Will Use or Disclose Your PHI and Purpose of Use/Disclosure**
Different people and groups will use and disclose your PHI. They will do this only in connection with the research study. The following persons or groups may use and/or disclose your PHI:
- The Principal Investigator and the research staff.
- The Principal Investigator may use other people and groups to help conduct the study. These people and groups will use your PHI to do this work.
- The following groups may also use and disclose your PHI. They will do this to make sure the research is done correctly and safely. The groups are:
  - The Emory University Institutional Review Board
We will use or disclose your PHI when we are required to do so by law. This includes laws that require us to report child abuse or elder abuse. We also will comply with legal requests or orders that require us to disclose your PHI. These include subpoenas or court orders.

**Expiration of Your Authorization**
As this is a research study, your authorization will not expire. You may, however, revoke your authorization later.

**Revoking Your Authorization**
You do not have to sign this form. Even if you do, at any time later on you may revoke (take back) your permission. If you want to do this, you must write to:

Nancy McCabe  
School of Nursing  
Emory University  
1520 Clifton Road, NE  
Atlanta, GA 30322

After that point, the researchers would not collect any more of your PHI. But they may use or pass along the information you already gave them so they can follow the law, protect your safety, or make sure the research was done properly. If you have any questions about this, please ask.

**Other Items You Should Know**
If we disclose information to people who do not have to follow the Privacy Rules, your information will no longer be protected by the Privacy Rules. People who do not have to follow the Privacy Rules can use or disclose your information with others without your permission if they are allowed to do so by the laws that cover them. Let us know if you have questions about this.

We will put a copy of your signed informed consent form for the research study and your signed HIPAA Authorization form into any medical record that you may have with Emory Healthcare facilities.

During the study you will generally not have access to records related to the research study. This is to preserve the integrity of the research. You may have access to these records when the study is complete. These records may include research related PHI your health care providers use to make decisions about your care. If necessary for your care, this information may be available to your doctor before the end of the study.

If identifiers are removed from your PHI, then the remaining information will not be subject to the Privacy Rules. It may be used or disclosed with other people or organizations, and/or for other purposes.

**Contacts**
If you have any questions regarding the study, you may call Nancy McCabe at (404) 234-1574.
If you have any questions about the study, or your rights as a study subject, you may contact the Emory University Institutional Review Board at 404-712-0720 or 1-877-503-9797, by email at irb@emory.edu.

**Authorization**
A copy of this form will be given to you.

______________________________________________________________
Signature of Study Subject

_________________________________________  ______________________
Date Time

______________________________________________________________
Printed Name of Study Subject

______________________________________________________________
Signature of Person Obtaining Authorization

_________________________________________  ______________________
Date Time

______________________________________________________________
Printed Name of Person Obtaining Authorization

_________________________________________  ______________________
Date Time
Incentives

Please complete the survey below.

Thank you!

MRN

_________________________

First Name

_________________________

Last Name

_________________________

Street, City, State, ZIP

_________________________

Phone number

_________________________

(Date of birth)

_________________________

Age (years)

_________________________

E-mail

_________________________

SIMPLE: Native disease
Isolated congenital aortic
valve disease
Isolated congenital mitral valve
disease (eg, except parachute valve,
cleft leaflet)
Small atrial septal defect
Isolated small ventricular septal defect (no associated
tissue)
Mild pulmonary stenosis
Small patent
ductus arteriosus
Repair conditions
Previously
ligated or occluded ductus arteriosus
Repair
secundum or sinus venosus atrial septal defect
without residual
Repair ventricular septal defect
without residual
Mild
MEDIUM: Aortic-left ventricular
fistula
Anomalous pulmonary venous drainage,
partial or total
Atrioventricular septal defects
(partial or complete)
Coarctation of the
aorta
Ebstein's anomaly
Infundibular right
ventricular outflow obstruction
Significance
Ostium primum atrial septal
defect
Patent ductus arteriosus (not
closed)
Pulmonary valve regurgitation (moderate to
severe)
Pulmonary valve stenosis (moderate to
severe)
Sinus of Valsalva fistula/aneurysm
Sinus
venosus atrial septal defect
Subvalvular AS or
SuprAAS (except HOCM)
Tetralogy of
Fallot
Ventricular septal defect
with
SEVERE: Conduits, valved or
nonvalved
Cyanotic congenital heart (all
forms)
Double-outlet ventricle
Eisenmenger
syndrome
Fontan procedure
Mitrales
Single
ventricle (also called double inlet or outlet,
common, or primitive)
Pulmonary atresia (all
forms)
Pulmonary vascular obstructive
disease
Transposition of the great
arteries
Tricuspid atresia
Truncus
arteriosus/hemitruncus
Other abnormalities of
atrioventricular or ventriculoarterial connection
not included above (ie, crisscross heart, isomerism,
heterotaxy syndromes, ventricular inversion)
Name of Primary Heart Defect

- AS
- ASD
- AVC
- BAV
- Cardiomyopathy
- CoArc
- Coronary anomaly
- DILV
- DORV
- Ebsteins anomaly
- Eisenmenger syndrome
- Heterotaxy
- HLHS
- HRHA
- Interrupted aortic arch
- Kawasaki
- Long QT
- LV non-compaction
- LVOTO
- MR
- MS
- MV Prolapse
- PA
- PAPVR
- PDA
- PFO
- PR
- PS
- RVOTO
- TA
- TAPVR
- TGA-D
- TGA-L
- TOF
- TR
- Truncus
- VSD
- Other
<table>
<thead>
<tr>
<th>Name of Secondary Heart Defects</th>
</tr>
</thead>
<tbody>
<tr>
<td>AS</td>
</tr>
<tr>
<td>ASD</td>
</tr>
<tr>
<td>AVC</td>
</tr>
<tr>
<td>BAV</td>
</tr>
<tr>
<td>Cardiomyopathy</td>
</tr>
<tr>
<td>CoArc</td>
</tr>
<tr>
<td>Coronary anomaly</td>
</tr>
<tr>
<td>DILV</td>
</tr>
<tr>
<td>DORV</td>
</tr>
<tr>
<td>Ebstein's anomaly</td>
</tr>
<tr>
<td>Eisenmenger syndrome</td>
</tr>
<tr>
<td>Heterotaxy</td>
</tr>
<tr>
<td>HLHS</td>
</tr>
<tr>
<td>HRHA</td>
</tr>
<tr>
<td>Interrupted aortic arch</td>
</tr>
<tr>
<td>Kawasaki</td>
</tr>
<tr>
<td>Long QT</td>
</tr>
<tr>
<td>LV non-compaction</td>
</tr>
<tr>
<td>LVOTO</td>
</tr>
<tr>
<td>MR</td>
</tr>
<tr>
<td>MS</td>
</tr>
<tr>
<td>MV Prolapse</td>
</tr>
<tr>
<td>PA</td>
</tr>
<tr>
<td>PAPVR</td>
</tr>
<tr>
<td>PDA</td>
</tr>
<tr>
<td>PFO</td>
</tr>
<tr>
<td>PR</td>
</tr>
<tr>
<td>PS</td>
</tr>
<tr>
<td>RVOTO</td>
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<tr>
<td>TA</td>
</tr>
<tr>
<td>TAPVR</td>
</tr>
<tr>
<td>TGA-D</td>
</tr>
<tr>
<td>TGA-L</td>
</tr>
<tr>
<td>TOF</td>
</tr>
<tr>
<td>TR</td>
</tr>
<tr>
<td>Truncus</td>
</tr>
<tr>
<td>VSD</td>
</tr>
<tr>
<td>Suprventricular arrhythmia</td>
</tr>
<tr>
<td>Ventricular arrhythmia</td>
</tr>
<tr>
<td>Bradyarrhythmia</td>
</tr>
<tr>
<td>Other</td>
</tr>
</tbody>
</table>

Total Number of Surgeries

- [ ] 0
- [ ] 1
- [ ] 2
- [ ] 3
- [ ] 4
- [ ] 5
- [ ] More than 5
<table>
<thead>
<tr>
<th>Name of First Surgery</th>
<th>ASD closure</th>
<th>ASO</th>
<th>AVC repair</th>
<th>Coarc repair</th>
<th>Fontan</th>
<th>Glenn</th>
<th>Mustard/Senning</th>
<th>MVR</th>
<th>Pacemaker</th>
<th>PDA closure</th>
<th>PFO closure</th>
<th>PVR</th>
<th>RVOT/LVOT conduit replacement</th>
<th>Shunt</th>
<th>Truncus repair</th>
<th>TVR</th>
<th>VSD closure</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age at First Surgery (years, include partial)</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Name of Second Surgery</td>
<td>ASD closure</td>
<td>ASO</td>
<td>AVC repair</td>
<td>Coarc repair</td>
<td>Fontan</td>
<td>Glenn</td>
<td>Mustard/Senning</td>
<td>MVR</td>
<td>Pacemaker</td>
<td>PDA closure</td>
<td>PFO closure</td>
<td>PVR</td>
<td>RVOT/LVOT conduit replacement</td>
<td>Shunt</td>
<td>Truncus repair</td>
<td>TVR</td>
<td>VSD closure</td>
<td>Other</td>
</tr>
<tr>
<td>Age at Second Surgery (years, include partial)</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Name of Third Surgery</td>
<td>ASD closure</td>
<td>ASO</td>
<td>AVC repair</td>
<td>Coarc repair</td>
<td>Fontan</td>
<td>Glenn</td>
<td>Mustard/Senning</td>
<td>MVR</td>
<td>Pacemaker</td>
<td>PDA closure</td>
<td>PFO closure</td>
<td>PVR</td>
<td>RVOT/LVOT conduit replacement</td>
<td>Shunt</td>
<td>Truncus repair</td>
<td>TVR</td>
<td>VSD closure</td>
<td>Other</td>
</tr>
<tr>
<td>Age at Third Surgery (years, include partial)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>
Name of Fourth Surgery

- ASD closure
- ASO
- AVC repair
- Coarc repair
- Fontan
- Glenn
- Mustard/Senning
- MVR
- Pacemaker
- PDA closure
- PFO closure
- PVR
- RVOT/LVOT conduit replacement
- Shunt
- Truncus repair
- TVR
- VSD closure
- Other

Name of Fifth Surgery

- ASD closure
- ASO
- AVC repair
- Coarc repair
- Fontan
- Glenn
- Mustard/Senning
- MVR
- Pacemaker
- PDA closure
- PFO closure
- PVR
- RVOT/LVOT conduit replacement
- Shunt
- Truncus repair
- TVR
- VSD closure
- Other

Age at Fourth Surgery (years, include partial if less than 1, round to nearest integer)

Age at Fifth Surgery (years, include partial if less than 1, round to nearest integer)

Developmental Delay?

- Yes
- No

Type Developmental Delay

- Down Syndrome
- Williams Syndrome
- Noonan Syndrome
- DiGeoge Syndrome
- CHARGE Syndrome
- Jacobsen Syndrome
- Turner Syndrome
- Alagille Syndrome
- VACTERL Syndrome
- Other

English-speaking

- Yes
- No

Further description for any "other" defects/surgeries/DD or to describe persons with >5 surgeries

PHQ-9 Total Score

(See notes on alert levels)
PHQ-9 Total Score Manual Calculation

(Calculate manually if missing any response.)
## Incentives contact

| Gift Card          | ○ Walmart  
|                    | ○ Amazon   
|                    | ○ Starbucks |
| Parking            | ○ Deck     
|                    | ○ Valet    |
| Date gift card #1: | __________________________ |
| E-mail Reminder 1  | __________________________ |
| E-mail Reminder 2  | __________________________ |
| E-mail Reminder 3  | __________________________ |
| Phone Reminder 1   | __________________________ |
| Phone Reminder 2   | __________________________ |
| Phone Reminder 3   | __________________________ |
| Notes              | __________________________ |
| Date gift card #2: | __________________________ |
| E-mail Reminder 1- HRU | __________________________ |
| E-mail Reminder 2-HRU | __________________________ |
| E-mail Reminder 3-HRU | __________________________ |
| E-mail Reminder 4-HRU | __________________________ |
| E-mail Reminder 5-HRU | __________________________ |
| E-mail Reminder 6-HRU | __________________________ |
| Phone Reminder 1-HRU | __________________________ |
| Phone Reminder 2-HRU | __________________________ |
| Phone Reminder 3-HRU | __________________________ |
| Phone Reminder 4-HRU | __________________________ |
| Phone Reminder 5-HRU | __________________________ |
| Phone Reminder 6-HRU | __________________________ |
| Notes:             | __________________________ |
ACHD_CHOI

Please complete the survey below.

Thank you!
Thank you for taking part in this study! Please answer the following questions. All your answers are confidential.

53) Gender
   - Female
   - Male

54) Ethnicity
   - Hispanic or Latino
   - NOT Hispanic or Latino

55) Race
   - American Indian/Alaska Native
   - Asian
   - Native Hawaiian or Other Pacific Islander
   - Black or African American
   - White
   - More Than One Race

56) What is your marital status?
   - Single
   - Married
   - Living with Partner
   - Divorced or separated
   - Widowed

57) Who do you live with? (Check all that apply)
   - Alone
   - With spouse
   - With parent(s)
   - With children
   - With siblings
   - With friends

58) What type of health insurance do you have?
   - Private Insurance
   - Medicaid or Medicare
   - Uninsured

59) What is your highest level of education?
   - Less than high school
   - High school
   - College degree
   - Graduate degree

60) What is your job status?
   - Employed full-time
   - Employed part-time
   - Homemaker
   - Student
   - Unemployed
   - On Disability

61) Who helps you the most in managing your heart condition?
   - Parent
   - Spouse or Partner
   - Sibling
   - Other Family Member
   - Friend

62) How does this person help you manage your heart condition? (Check all that apply)
   - Making doctor's appointments
   - Transportation to appointments
   - Getting my medications
   - Reminding me to take medications
   - Deciding if I need to see the doctor
   - Making decisions about my medical care
   - Encouraging me to stay healthy (exercise, healthy diet, stop smoking, or limit alcohol)
   - Providing me with support when I am sad or anxious about my heart condition

63) How much help do you RECEIVE from your family to manage your heart condition? Tap on the white bar to move the blue box.
64) How much help to you WANT to receive from your family to manage your heart condition? Tap on the white bar to move the blue box.

I do not want any help
I want help with everything

(Place a mark on the scale above)

65) How many friends do you have with a congenital heart defect?

○ 0
○ 1
○ 2
○ 3
○ 4
○ 5 or more
Please answer the following questions.

66) How satisfied are you with the overall quality of your life?  
   Tap on the white bar to move to blue square.

   Not at all satisfied

   Completely satisfied

   (Place a mark on the scale above)

67) Compared to people your own age, how would you rate your quality of life?  
   Tap on the white bar to move to blue square.

   Much worse

   Much better

   (Place a mark on the scale above)

68) How satisfied are you with your current health?  
   Tap on the white bar to move to blue square.

   Not at all satisfied

   Completely satisfied

   (Place a mark on the scale above)
<table>
<thead>
<tr>
<th>Question</th>
<th>Without any difficulty</th>
<th>With a little difficulty</th>
<th>With some difficulty</th>
<th>With much difficulty</th>
<th>Unable to do</th>
</tr>
</thead>
<tbody>
<tr>
<td>69) Are you able to do chores such as vacuuming or yard work?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>70) Are you able to go up and down stairs at a normal pace?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>71) Are you able to go for a walk of at least 15 minutes?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>72) Are you able to run errands and shop?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
Please respond to each question or statement by marking one answer per row.

<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>73) In the past 7 days, I felt fearful.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>74) In the past 7 days, I found it hard to focus on anything other than my anxiety.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>75) In the past 7 days, my worries overwhelmed me.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>76) In the past 7 days, I felt uneasy.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td></td>
<td>Question</td>
<td>Never</td>
<td>Rarely</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>---</td>
<td>-------------------------------------------------------------------------</td>
<td>-------</td>
<td>--------</td>
<td>-----------</td>
<td>-------</td>
</tr>
<tr>
<td>77)</td>
<td>During the past 7 days, I felt worthless.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>78)</td>
<td>During the past 7 days, I felt helpless.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>79)</td>
<td>During the past 7 days, I felt depressed.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>80)</td>
<td>During the past 7 days, I felt hopeless.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

Please respond to each question or statement by marking one answer per row.
Please respond to each question or statement by marking one answer per row.

<table>
<thead>
<tr>
<th></th>
<th>Question</th>
<th>Not at all</th>
<th>A little bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>81</td>
<td>During the past 7 days, I feel fatigued.</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>82</td>
<td>During the past 7 days, I have trouble starting things because I am tired.</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>83</td>
<td>In the past 7 days, how run-down did you feel on average?</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>84</td>
<td>In the past 7 days, how fatigued were you on average?</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
</tbody>
</table>
Please respond to each question or statement by marking one answer per row.

<table>
<thead>
<tr>
<th>Question</th>
<th>Very poor</th>
<th>Poor</th>
<th>Fair</th>
<th>Good</th>
<th>Very good</th>
</tr>
</thead>
<tbody>
<tr>
<td>85) In the past 7 days, my sleep quality was…..</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>86) In the past 7 days, my sleep was refreshing.</td>
<td>Not at all</td>
<td>A little bit</td>
<td>Somewhat</td>
<td>Quite a bit</td>
<td>Very much</td>
</tr>
<tr>
<td>87) In the past 7 days, I had a problem with my sleep.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>88) In the past 7 days, I had difficulty falling asleep.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Question</td>
<td>Not at all</td>
<td>A little bit</td>
<td>Somewhat</td>
<td>Quite a bit</td>
<td>Very much</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>------------</td>
<td>--------------</td>
<td>----------</td>
<td>-------------</td>
<td>-----------</td>
</tr>
<tr>
<td>89) In the past 7 days, I am satisfied with how much work I can do</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(include work at home).</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td></td>
<td>○</td>
</tr>
<tr>
<td>90) In the past 7 days, I am satisfied with my ability to work</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td></td>
<td>○</td>
</tr>
<tr>
<td>(include work at home).</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>91) In the past 7 days, I am satisfied with my ability to do regular</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td></td>
<td>○</td>
</tr>
<tr>
<td>personal and household responsibilities.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>92) In the past 7 days, I am satisfied with my ability to perform my</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td></td>
<td>○</td>
</tr>
<tr>
<td>daily routines.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Please respond to each question or statement by marking one answer per row.

<table>
<thead>
<tr>
<th></th>
<th>In the past 7 days, how much did pain interfere with your day to day activities?</th>
</tr>
</thead>
<tbody>
<tr>
<td>93</td>
<td>Not at all</td>
</tr>
<tr>
<td></td>
<td>○</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>In the past 7 days, how much did pain interfere with work around the home?</th>
</tr>
</thead>
<tbody>
<tr>
<td>94</td>
<td>Not at all</td>
</tr>
<tr>
<td></td>
<td>○</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>In the past 7 days, how much did pain interfere with your ability to participate in social activities?</th>
</tr>
</thead>
<tbody>
<tr>
<td>95</td>
<td>Not at all</td>
</tr>
<tr>
<td></td>
<td>○</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>In the past 7 days, how much did pain interfere with your household chores?</th>
</tr>
</thead>
<tbody>
<tr>
<td>96</td>
<td>Not at all</td>
</tr>
<tr>
<td></td>
<td>○</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>In the past 7 days, how would you rate your pain on average?</th>
</tr>
</thead>
<tbody>
<tr>
<td>97</td>
<td>○ 0=no pain</td>
</tr>
</tbody>
</table>


Self-care

Please complete the survey below.

Thank you!
Thank you for taking part in this study! You are about to take several surveys. Your answers are confidential. It will probably take you between 1 to 2 hours to complete the surveys. You can take breaks as often as you need.

Please contact Nancy McCabe at 404-234-1574 or nmccabe@emory.edu if you have any questions.

What is the name of your heart defect?

How many heart surgeries have you had?

○ 0
○ 1
○ 2
○ 3
○ 4
○ 5
○ More than 5

List all of the heart surgeries you have had

Do you have any medical conditions other than your heart defect?

○ Yes
○ No

List your other medical conditions.

Please list your current medications and dosages.

What is your current exercise recommendation? (Check all that apply)

○ No restrictions
○ Avoid contact sports (such as football or hockey).
○ Gentle exercise only (such as walking).
○ Avoid competitive sports
○ Avoid heavy lifting (weight that makes you strain or get red in the face).

Check all special precautions that apply to you.

○ Flu shot recommended
○ Avoid metal detectors
○ Supplemental oxygen for air travel recommended
○ Avoid traveling to high elevations (>5,000 feet)
○ Take antibiotics prior to dental procedures
○ Notify my providers to take blood pressure in only one arm. My pressure is lower in one arm than in the other because of a prior surgery.
○ Eat a low-salt diet (< 2,000 mg per day)
○ Always use air filters when getting IV fluids or medications

Do you have an advance directive?

○ Yes
○ No
○ I do not know

Are you a woman?

○ Yes
○ No

What is your current pregnancy recommendation?

○ Pregnancy not currently recommended because of risk to me and my baby.
○ Consultation with my heart doctor prior to becoming pregnant.
○ Planned pregnancy under direct supervision of my heart doctor.
○ No restrictions. My risk is the same as for women without a heart defect.
What is your current contraception recommendation?

- Progestin only
- Low dose estrogen/progestin
- Barrier method (such as condoms or diaphragms)
- IUD (such as paraguard, marina)
- No special recommendations. My risks are the same as a woman without a heart defect.
- Not applicable (hysterectomy, tubal ligation, or menopause)
For each of the following questions, please choose the number that corresponds to your confidence at the present time.

<table>
<thead>
<tr>
<th>Question</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>Totally confident 10</th>
</tr>
</thead>
<tbody>
<tr>
<td>How confident are you that you can get family to help you with the things you need (such as household chores like shopping, cooking, or transport)?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>How confident are you that you can get emotional support from family (such as listening or talking over your problems)?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>How confident are you that you can get emotional support from resources other than family, if needed?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>How confident are you that you can get help with your daily tasks (such as housecleaning, yard work, meals, or personal hygiene) from resources other than family if needed?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
Please answer the following questions.

Do you currently take medications?  
- Yes  
- No

Are you a woman and physically able to have children?  
- Yes  
- No
Think about how you have been feeling in the last month as you complete these questions.

Listed below are common instructions given to people with congenital heart defects. How often do you do the following?

<table>
<thead>
<tr>
<th>Activity</th>
<th>Never</th>
<th>Sometimes</th>
<th>Frequently</th>
<th>Always or daily</th>
</tr>
</thead>
<tbody>
<tr>
<td>Keep your heart doctor appointments?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Use tobacco products (cigarettes, chew, snuff)?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Drink more than 3 alcoholic beverages per week?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Try to maintain a health weight?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Make healthy food choices?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Call your heart doctor before having minor surgeries or procedures?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Take care of your teeth (brushing, going to the dentist)?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Exercise at least 3 days per week?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Get 7-8 hours of sleep?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Take some time to relax each day?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Spend time with close friends?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Take medications as prescribed?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Use a system, such as a pillbox, to help you remember your medications?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Forget to take a medication?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Use birth control?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Make a plan with your heart doctor before becoming pregnant?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>
People with congenital heart defects may have changes in the way they feel or notice that their heart is causing health problems. How often do you:

<table>
<thead>
<tr>
<th>Activity</th>
<th>Never or rarely</th>
<th>Sometimes</th>
<th>Frequently</th>
<th>Always or daily</th>
</tr>
</thead>
<tbody>
<tr>
<td>Check you ankles for swelling?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Attribute being more tired than usual on your heart?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Watch for changes in the way you feel?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Experience side effects of medication?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Watch for heart symptoms when you have the flu or other illness?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Feel if your heart beats too fast or too slow?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>
People with congenital heart defects sometimes experience symptoms. Have you had any symptoms related to your heart defect in the past MONTH? [Common symptoms include irregular heart beats, chest pain, passing out, shortness of breath, sudden weakness, tired doing usual activities, blueness of nailbeds or lips, or abdominal or ankle swelling]

○ Yes
○ No
### How likely were you to try one of these actions to relieve your symptoms?

<table>
<thead>
<tr>
<th>Action</th>
<th>Not likely</th>
<th>Somewhat likely</th>
<th>Likely</th>
<th>Very likely</th>
</tr>
</thead>
<tbody>
<tr>
<td>Change your activity level (slow down, rest)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Call your doctor or nurse for guidance.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Take an extra medication.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Not confident</td>
<td>Somewhat confident</td>
<td>Very confident</td>
<td>Extremely confident</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>--------------</td>
<td>-------------------</td>
<td>---------------</td>
<td>--------------------</td>
</tr>
<tr>
<td>Keep yourself free of symptoms?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Follow the treatment advice you have been given?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Recognize changes in your health?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Evaluate the importance of your symptoms?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Do something that will relieve your symptoms?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Evaluate how well an action works to relieve your symptoms?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Question</td>
<td>Options</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
<td>----------------------------------------------</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In the past month, have you experienced shortness of breath performing your usual activities?</td>
<td>Yes, No</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How FREQUENTLY did you experience shortness of breath performing your usual activities?</td>
<td>Rarely, A few days, Half the days, Most days, Everyday</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How SEVERE was the shortness of breath performing your usual activities?</td>
<td>Not Severe At All, A Little Severe, Somewhat Severe, Moderately Severe, Very Severe</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How much did the shortness of breath performing your usual activities affect your enjoyment of life?</td>
<td>Not At All, A Little Bit, Somewhat, A Lot, A Great Deal</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In the past month, have you experienced shortness of breath at rest?</td>
<td>Yes, No</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How frequently did you experience shortness of breath at rest?</td>
<td>Rarely, A few days, Half the days, Most days, Everyday</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How severe was shortness of breath at rest?</td>
<td>Not Severe At All, A Little Severe, Somewhat Severe, Moderately Severe, Very Severe</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How much did having shortness of breath at rest affect your enjoyment of life?</td>
<td>Not At All, A Little Bit, Somewhat, A Lot, A Great Deal</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In the past month, have you experienced shortness of breath that wakes you up at night?</td>
<td>Yes, No</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How frequently did you experience shortness of breath that wakes you up at night?</td>
<td>Rarely, A few days, Half the days, Most days, Everyday</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How severe was the shortness of breath that wakes you up at night?</td>
<td>Not Severe At All, A Little Severe, Somewhat Severe, Moderately Severe, Very Severe</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How much did the shortness of breath that wakes you up at night affect your enjoyment of life?</td>
<td>Not At All, A Little Bit, Somewhat, A Lot, A Great Deal</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
In the past month, have you experienced difficulty climbing stairs or walking your usual distance?

○ Yes
○ No

How frequently did you experience difficulty climbing stairs or walking your usual distance?

○ Rarely
○ A few days
○ Half the days
○ Most days
○ Everyday

How severe was difficulty climbing stairs or walking your usual distance?

○ Not Severe At All
○ A Little Severe
○ Somewhat Severe
○ Moderately Severe
○ Very Severe

How much did the difficulty climbing stairs or walking your usual distance affect your enjoyment of life?

○ Not At All
○ A Little Bit
○ Somewhat
○ A Lot
○ A Great Deal

In the past month, have you been unable to complete daily chores or activities?

○ Yes
○ No

How frequently were you unable to complete daily chores or activities?

○ Rarely
○ A few days
○ Half the days
○ Most days
○ Everyday

How severe was the inability to complete daily chores or activities?

○ Not Severe At All
○ A Little Severe
○ Somewhat Severe
○ Moderately Severe
○ Very Severe

How much did the inability to complete daily chores or activities affect your enjoyment of life?

○ Not At All
○ A Little Bit
○ Somewhat
○ A Lot
○ A Great Deal

In the past month, have you felt tired or a lack of energy?

○ Yes
○ No

How frequently did you feel tired or a lack of energy?

○ Rarely
○ A few days
○ Half the days
○ Most days
○ Everyday

How severe was your tiredness?

○ Not Severe At All
○ A Little Severe
○ Somewhat Severe
○ Moderately Severe
○ Very Severe

How much did being tired affect your enjoyment of life?

○ Not At All
○ A Little Bit
○ Somewhat
○ A Lot
○ A Great Deal
<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>In the past month, have you had swelling in your feet, ankles, or abdomen?</td>
<td>Yes, No</td>
</tr>
<tr>
<td>How frequently did you experience swelling in your feet, ankles, or abdomen?</td>
<td>Rarely, A few days, Half the days, Most days, Everyday</td>
</tr>
<tr>
<td>How severe was the swelling in your feet, ankles, or abdomen?</td>
<td>Not Severe At All, A Little Severe, Somewhat Severe, Moderately Severe, Very Severe</td>
</tr>
<tr>
<td>How much did the swelling in your feet, ankles, or abdomen affect your enjoyment of life?</td>
<td>Not At All, A Little Bit, Somewhat, A Lot, A Great Deal</td>
</tr>
<tr>
<td>In the past month, have you had excessive sweating?</td>
<td>Yes, No</td>
</tr>
<tr>
<td>How frequently did you experience the excessive sweating?</td>
<td>Rarely, A few days, Half the days, Most days, Everyday</td>
</tr>
<tr>
<td>How severe was the excessive sweating?</td>
<td>Not Severe At All, A Little Severe, Somewhat Severe, Moderately Severe, Very Severe</td>
</tr>
<tr>
<td>How much did the excessive sweating affect your enjoyment of life?</td>
<td>Not At All, A Little Bit, Somewhat, A Lot, A Great Deal</td>
</tr>
<tr>
<td>In the past month, have you had chest pressure or chest pain?</td>
<td>Yes, No</td>
</tr>
<tr>
<td>How frequently did you experience chest pressure or chest pain?</td>
<td>Rarely, A few days, Half the days, Most days, Everyday</td>
</tr>
<tr>
<td>How severe was the chest pressure or chest pain?</td>
<td>Not Severe At All, A Little Severe, Somewhat Severe, Moderately Severe, Very Severe</td>
</tr>
<tr>
<td>How much did the chest pressure or chest pain affect your enjoyment of life?</td>
<td>Not At All, A Little Bit, Somewhat, A Lot, A Great Deal</td>
</tr>
</tbody>
</table>
In the past month, have you had fluttering in your chest (palpitations or racing heart)?

○ Yes
○ No

How frequently did you experience fluttering in your chest (palpitations or racing heart)?

○ Rarely
○ A few days
○ Half the days
○ Most days
○ Everyday

How severe was the fluttering in your chest (palpitations or racing heart)?

○ Not Severe At All
○ A Little Severe
○ Somewhat Severe
○ Moderately Severe
○ Very Severe

How much did the fluttering in your chest (palpitations or racing heart) affect your enjoyment of life?

○ Not At All
○ A Little Bit
○ Somewhat
○ A Lot
○ A Great Deal

In the past month, have you had difficulty sleeping?

○ Yes
○ No

How frequently did you experience difficulty sleeping?

○ Rarely
○ A few days
○ Half the days
○ Most days
○ Everyday

How severe was the difficulty sleeping?

○ Not Severe At All
○ A Little Severe
○ Somewhat Severe
○ Moderately Severe
○ Very Severe

How much did the difficulty sleeping affect your enjoyment of life?

○ Not At All
○ A Little Bit
○ Somewhat
○ A Lot
○ A Great Deal

In the past month, have you had difficulty concentrating or forgetfulness?

○ Yes
○ No

How frequently did you experience difficulty concentrating or forgetfulness?

○ Rarely
○ A few days
○ Half the days
○ Most days
○ Everyday

How severe was the difficulty concentrating or forgetfulness?

○ Not Severe At All
○ A Little Severe
○ Somewhat Severe
○ Moderately Severe
○ Very Severe

How much did difficulty concentrating or forgetfulness affect your enjoyment of life?

○ Not At All
○ A Little Bit
○ Somewhat
○ A Lot
○ A Great Deal
<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>In the past month, have you had bleeding due to blood thinners?</td>
<td>Yes, No</td>
</tr>
<tr>
<td>How frequently did you experience bleeding due to blood thinners?</td>
<td>Rarely, A few days, Half the days, Most days, Everyday</td>
</tr>
<tr>
<td>How severe was the bleeding due to blood thinners?</td>
<td>Not Severe At All, A Little Severe, Somewhat Severe, Moderately Severe, Very Severe</td>
</tr>
<tr>
<td>How much did the bleeding due to blood thinners affect your enjoyment of life?</td>
<td>Not At All, A Little Bit, Somewhat, A Lot, A Great Deal</td>
</tr>
<tr>
<td>In the past month, have you had a headache?</td>
<td>Yes, No</td>
</tr>
<tr>
<td>How frequently did you experience a headache?</td>
<td>Rarely, A few days, Half the days, Most days, Everyday</td>
</tr>
<tr>
<td>How severe was the headache?</td>
<td>Not Severe At All, A Little Severe, Somewhat Severe, Moderately Severe, Very Severe</td>
</tr>
<tr>
<td>How much did the headache affect your enjoyment of life?</td>
<td>Not At All, A Little Bit, Somewhat, A Lot, A Great Deal</td>
</tr>
<tr>
<td>In the past month, have you had dizziness or lightheadedness?</td>
<td>Yes, No</td>
</tr>
<tr>
<td>How frequently did you experience dizziness or lightheadedness?</td>
<td>Rarely, A few days, Half the days, Most days, Everyday</td>
</tr>
<tr>
<td>How severe was the dizziness or lightheadedness?</td>
<td>Not Severe At All, A Little Severe, Somewhat Severe, Moderately Severe, Very Severe</td>
</tr>
<tr>
<td>How much did the dizziness or lightheadedness affect your enjoyment of life?</td>
<td>Not At All, A Little Bit, Somewhat, A Lot, A Great Deal</td>
</tr>
<tr>
<td>Question</td>
<td>Options</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| In the past month, have you experience fainting or passing out?         | ○ Yes  
○ No                                                                 |
| How frequently did you experience fainting or passing out?              | ○ Rarely  
○ A few days  
○ Half the days  
○ Most days  
○ Everyday                                                                 |
| How severe was the fainting or passing out?                             | ○ Not Severe At All  
○ A Little Severe  
○ Somewhat Severe  
○ Moderately Severe  
○ Very Severe                                                                 |
| How much did the fainting or passing out affect your enjoyment of life?  | ○ Not At All  
○ A Little Bit  
○ Somewhat  
○ A Lot  
○ A Great Deal                                                                 |
| In the past month, have you had purple/blueness of nailbeds or lips?    | ○ Yes  
○ No                                                                 |
| How frequently did you experience purple/blueness of nailbeds or lips?  | ○ Rarely  
○ A few days  
○ Half the days  
○ Most days  
○ Everyday                                                                 |
| How severe was the purple/blueness of nailbeds or lips?                 | ○ Not Severe At All  
○ A Little Severe  
○ Somewhat Severe  
○ Moderately Severe  
○ Very Severe                                                                 |
| How much did the purple/blueness of nailbeds or lips affect your enjoyment of life? | ○ Not At All  
○ A Little Bit  
○ Somewhat  
○ A Lot  
○ A Great Deal                                                                 |
| In the past month, have you had abdominal pain or discomfort?           | ○ Yes  
○ No                                                                 |
| How frequently did you experience abdominal pain or discomfort?         | ○ Rarely  
○ A few days  
○ Half the days  
○ Most days  
○ Everyday                                                                 |
| How severe was the abdominal pain or discomfort?                        | ○ Not Severe At All  
○ A Little Severe  
○ Somewhat Severe  
○ Moderately Severe  
○ Very Severe                                                                 |
| How much did the abdominal pain or discomfort affect your enjoyment of life? | ○ Not At All  
○ A Little Bit  
○ Somewhat  
○ A Lot  
○ A Great Deal                                                                 |
<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>In the past month, have you had muscle cramps?</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>No</td>
</tr>
<tr>
<td>How frequently did you experience muscle cramps?</td>
<td>Rarely</td>
</tr>
<tr>
<td></td>
<td>A few days</td>
</tr>
<tr>
<td></td>
<td>Half the days</td>
</tr>
<tr>
<td></td>
<td>Most days</td>
</tr>
<tr>
<td></td>
<td>Everyday</td>
</tr>
<tr>
<td>How severe were the muscle cramps?</td>
<td>Not Severe At All</td>
</tr>
<tr>
<td></td>
<td>A Little Severe</td>
</tr>
<tr>
<td></td>
<td>Somewhat Severe</td>
</tr>
<tr>
<td></td>
<td>Moderately Severe</td>
</tr>
<tr>
<td></td>
<td>Very Severe</td>
</tr>
<tr>
<td>How much did the muscle cramps affect your enjoyment of life?</td>
<td>Not At All</td>
</tr>
<tr>
<td></td>
<td>A Little Bit</td>
</tr>
<tr>
<td></td>
<td>Somewhat</td>
</tr>
<tr>
<td></td>
<td>A Lot</td>
</tr>
<tr>
<td></td>
<td>A Great Deal</td>
</tr>
<tr>
<td>In the past month, have you felt irritable?</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>No</td>
</tr>
<tr>
<td>How frequently did you experience irritability?</td>
<td>Rarely</td>
</tr>
<tr>
<td></td>
<td>A few days</td>
</tr>
<tr>
<td></td>
<td>Half the days</td>
</tr>
<tr>
<td></td>
<td>Most days</td>
</tr>
<tr>
<td></td>
<td>Everyday</td>
</tr>
<tr>
<td>How severe was the irritability?</td>
<td>Not Severe At All</td>
</tr>
<tr>
<td></td>
<td>A Little Severe</td>
</tr>
<tr>
<td></td>
<td>Somewhat Severe</td>
</tr>
<tr>
<td></td>
<td>Moderately Severe</td>
</tr>
<tr>
<td></td>
<td>Very Severe</td>
</tr>
<tr>
<td>How much did the irritability affect your enjoyment of life?</td>
<td>Not At All</td>
</tr>
<tr>
<td></td>
<td>A Little Bit</td>
</tr>
<tr>
<td></td>
<td>Somewhat</td>
</tr>
<tr>
<td></td>
<td>A Lot</td>
</tr>
<tr>
<td></td>
<td>A Great Deal</td>
</tr>
<tr>
<td>In the past month, have you felt worried?</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>No</td>
</tr>
<tr>
<td>How frequently did you experience worry?</td>
<td>Rarely</td>
</tr>
<tr>
<td></td>
<td>A few days</td>
</tr>
<tr>
<td></td>
<td>Half the days</td>
</tr>
<tr>
<td></td>
<td>Most days</td>
</tr>
<tr>
<td></td>
<td>Everyday</td>
</tr>
<tr>
<td>How severe was the worry?</td>
<td>Not Severe At All</td>
</tr>
<tr>
<td></td>
<td>A Little Severe</td>
</tr>
<tr>
<td></td>
<td>Somewhat Severe</td>
</tr>
<tr>
<td></td>
<td>Moderately Severe</td>
</tr>
<tr>
<td></td>
<td>Very Severe</td>
</tr>
<tr>
<td>How much did the worrying affect your enjoyment of life?</td>
<td>Not At All</td>
</tr>
<tr>
<td></td>
<td>A Little Bit</td>
</tr>
<tr>
<td></td>
<td>Somewhat</td>
</tr>
<tr>
<td></td>
<td>A Lot</td>
</tr>
<tr>
<td></td>
<td>A Great Deal</td>
</tr>
</tbody>
</table>
In the past month, have you felt sad?
- Yes
- No

How frequently did you experience sadness?
- Rarely
- A few days
- Half the days
- Most days
- Everyday

How severe was the sadness?
- Not Severe At All
- A Little Severe
- Somewhat Severe
- Moderately Severe
- Very Severe

How much did the sadness affect your enjoyment of life?
- Not At All
- A Little Bit
- Somewhat
- A Lot
- A Great Deal

In the past month, have you had a lack of interest or problems with sexual functioning?
- Yes
- No

How frequently did you experience a lack of interest or problems with sexual functioning?
- Rarely
- A few days
- Half the days
- Most days
- Everyday

How severe was the lack of interest or problems with sexual functioning?
- Not Severe At All
- A Little Severe
- Somewhat Severe
- Moderately Severe
- Very Severe

How much did the lack of interest or problems with sexual functioning affect your enjoyment of life?
- Not At All
- A Little Bit
- Somewhat
- A Lot
- A Great Deal
Over the last 2 WEEKS, how often have you been bothered by any of the following problems?

1. Little interest or pleasure in doing things
   - Not at all
   - Several days
   - More than half the days
   - Nearly every day

2. Feeling down, depressed, or hopeless
   - Not at all
   - Several days
   - More than half the days
   - Nearly every day

3. Trouble falling or staying asleep or sleeping too much
   - Not at all
   - Several days
   - More than half the days
   - Nearly every day

4. Feeling tired or having little energy
   - Not at all
   - Several days
   - More than half the days
   - Nearly every day

5. Poor appetite or overeating
   - Not at all
   - Several days
   - More than half the days
   - Nearly every day

6. Feeling bad about yourself?
   - Not at all
   - Several days
   - More than half the days
   - Nearly every day

7. Trouble concentrating on things?
   - Not at all
   - Several days
   - More than half the days
   - Nearly every day

8. Moving or speaking so slowly that other people could have noticed
   - Not at all
   - Several days
   - More than half the days
   - Nearly every day

9. Thoughts that you would be better off dead or of hurting yourself in some way
   - Not at all
   - Several days
   - More than half the days
   - Nearly every day
This questionnaire lists various attitudes and behaviors of parents. As you remember your mother (or primary caregiver) in your first 16 years of life, place a check in the most appropriate box next to each question.

<table>
<thead>
<tr>
<th>Behavior</th>
<th>Very like</th>
<th>Moderately like</th>
<th>Moderately unlike</th>
<th>Very unlike</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spoke to me in a warm and friendly voice</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did not help me as much as I needed</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Let me do those things I like doing</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Seemed emotionally cold to me</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Appeared to understand my problems and worries</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Was affectionate to me</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Liked me to make my own decisions</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did not want me to grow up</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tried to control everything I did</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Invaded my privacy</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Enjoyed talking things over with me</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frequently smiled at me</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
This questionnaire lists various attitudes and behaviors of parents. As you remember your mother (or primary caregiver) in your first 16 years of life, place a check in the most appropriate box next to each question.

<table>
<thead>
<tr>
<th>Attitude or Behavior</th>
<th>Box 1</th>
<th>Box 2</th>
<th>Box 3</th>
<th>Box 4</th>
<th>Box 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tended to baby me</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Did not seem to understand what I needed or wanted</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Let me decide things for myself</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Made me feel I wasn’t wanted</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Could make me feel better when I was upset</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Did not talk with me very much</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Tried to make me feel dependent on her/him</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Felt I could not look after myself unless she/he was around</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Gave me as much freedom as I wanted</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Let me go out as often as I wanted</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Was overprotective of me</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Did not praise me</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Let me dress in any way I pleased</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
Health Resource Use 1

Please complete the survey below.

Thank you!
Please answer the following questions.

In the past month, how many times did you visit a doctor?

- 0
- 1
- 2
- 3
- 4
- 5

At your FIRST visit, what kind of doctor did you see?

- Primary Care Provider
- Psychologist or Counselor
- Heart Doctor
- Pacemaker Doctor
- Lung Doctor
- Liver Doctor
- Kidney Doctor
- Diabetes Doctor
- Surgery Doctor
- Other

Was this doctor's appointment at Emory?

- Yes
- No

What was the reason you had to go to the doctor?

At your SECOND visit, what kind of doctor did you see?

- Primary Care Provider
- Psychologist or Counselor
- Heart Doctor
- Pacemaker Doctor
- Lung Doctor
- Liver Doctor
- Kidney Doctor
- Diabetes Doctor
- Surgery Doctor
- Other

Was this doctor's appointment at Emory?

- Yes
- No

What was the reason you had to go to the doctor?

At your THIRD visit, what kind of doctor did you see?

- Primary Care Provider
- Psychologist or Counselor
- Heart Doctor
- Pacemaker Doctor
- Lung Doctor
- Liver Doctor
- Kidney Doctor
- Diabetes Doctor
- Surgery Doctor
- Other

Was this doctor's appointment at Emory?

- Yes
- No

What was the reason you had to go to the doctor?
At your FOURTH visit, what kind of doctor did you see?

- Primary Care Provider
- Psychologist or Counselor
- Heart Doctor
- Pacemaker Doctor
- Lung Doctor
- Liver Doctor
- Kidney Doctor
- Diabetes Doctor
- Surgery Doctor
- Other

Was this doctor's appointment at Emory?

- Yes
- No

What was the reason you had to go to the doctor?

At your FIFTH visit, what kind of doctor did you see?

- Primary Care Provider
- Psychologist or Counselor
- Heart Doctor
- Pacemaker Doctor
- Lung Doctor
- Liver Doctor
- Kidney Doctor
- Diabetes Doctor
- Surgery Doctor
- Other

Was this doctor's appointment at Emory?

- Yes
- No

What was the reason you had to go to the doctor?
In the past month, how many times did you go to the emergency room?

- 0
- 1
- 2
- 3

At your FIRST emergency room visit, did you go to the Emory emergency room?

- Yes
- No

What was the reason you had to go to the emergency room?

______________________________

List any tests or procedures you had done in the Emergency Room

______________________________

At your SECOND emergency room visit, did you go to the Emergency Room at Emory?

- Yes
- No

What was the reason you had to go to the emergency room?

______________________________

List any tests or procedures you had done in the Emergency Room

______________________________

At your THIRD emergency room visit, did you go to the Emergency Room at Emory?

- Yes
- No

What was the reason you had to go to the emergency room?

______________________________

List any tests or procedures you had done in the Emergency Room

______________________________
In the past month, how many times were you hospitalized?  
○ 0  ○ 1  ○ 2  ○ 3

At your FIRST hospitalization, did you go to Emory?  
○ Yes  ○ No

How many days were you in the hospital?  
________________________

What was the reason you were hospitalized?  
________________________

List any tests or procedures you had done in the hospital.  
________________________

At your SECOND hospitalization, did you go to Emory?  
○ Yes  ○ No

How many days were you in the hospital?  
________________________

What was the reason you were hospitalized?  
________________________

List any tests or procedures you had done in the hospital.  
________________________

At your THIRD hospitalization, did you go to Emory?  
○ Yes  ○ No

How many days were you in the hospital?  
________________________

What was the reason you were hospitalized?  
________________________

List any tests or procedures you had done in the hospital.  
________________________
Health Resource Use 2

Please complete the survey below.

Thank you!

In the past month, how many times did you visit a doctor?

- 0
- 1
- 2
- 3
- 4
- 5

At your FIRST visit, what kind of doctor did you see?

- Primary Care Provider
- Psychologist or Counselor
- Heart Doctor
- Pacemaker Doctor
- Lung Doctor
- Liver Doctor
- Kidney Doctor
- Diabetes Doctor
- Surgery Doctor
- Other

Was this doctor's appointment at Emory?

- Yes
- No

What was the reason you had to go to the doctor?

At your SECOND visit, what kind of doctor did you see?

- Primary Care Provider
- Psychologist or Counselor
- Heart Doctor
- Pacemaker Doctor
- Lung Doctor
- Liver Doctor
- Kidney Doctor
- Diabetes Doctor
- Surgery Doctor
- Other

Was this doctor's appointment at Emory?

- Yes
- No

What was the reason you had to go to the doctor?

At your THIRD visit, what kind of doctor did you see?

- Primary Care Provider
- Psychologist or Counselor
- Heart Doctor
- Pacemaker Doctor
- Lung Doctor
- Liver Doctor
- Kidney Doctor
- Diabetes Doctor
- Surgery Doctor
- Other

Was this doctor's appointment at Emory?

- Yes
- No

What was the reason you had to go to the doctor?
At your FOURTH visit, what kind of doctor did you see?

- Primary Care Provider
- Psychologist or Counselor
- Heart Doctor
- Pacemaker Doctor
- Lung Doctor
- Liver Doctor
- Kidney Doctor
- Diabetes Doctor
- Surgery Doctor
- Other

Was this doctor’s appointment at Emory?

- Yes
- No

What was the reason you had to go to the doctor?

At your FIFTH visit, what kind of doctor did you see?

- Primary Care Provider
- Psychologist or Counselor
- Heart Doctor
- Pacemaker Doctor
- Lung Doctor
- Liver Doctor
- Kidney Doctor
- Diabetes Doctor
- Surgery Doctor
- Other

Was this doctor’s appointment at Emory?

- Yes
- No

What was the reason you had to go to the doctor?
In the past month, how many times did you go to the emergency room?  
- 0  
- 1  
- 2  
- 3  

At your FIRST emergency room visit, did you go to the Emory emergency room?  
- Yes  
- No  

What was the reason you had to go to the emergency room?  

List any tests or procedures you had done in the Emergency Room  

At your SECOND emergency room visit, did you go to the Emergency Room at Emory?  
- Yes  
- No  

What was the reason you had to go to the emergency room?  

List any tests or procedures you had done in the Emergency Room  

At your THIRD emergency room visit, did you go to the Emergency Room at Emory?  
- Yes  
- No  

What was the reason you had to go to the emergency room?  

List any tests or procedures you had done in the Emergency Room  

In the past month, how many times were you hospitalized?

- 0
- 1
- 2
- 3

At your FIRST hospitalization, did you go to Emory?

- Yes
- No

How many days were you in the hospital?

________________________

What was the reason you were hospitalized?

________________________

List any tests or procedures you had done in the hospital.

________________________

At your SECOND hospitalization, did you go to Emory?

- Yes
- No

How many days were you in the hospital?

________________________

What was the reason you were hospitalized?

________________________

List any tests or procedures you had done in the hospital.

________________________

At your THIRD hospitalization, did you go to Emory?

- Yes
- No

How many days were you in the hospital?

________________________

What was the reason you were hospitalized?

________________________

List any tests or procedures you had done in the hospital.

________________________
Health Resource Use 3

Please complete the survey below.

Thank you!

In the past month, how many times did you visit a doctor?

- 0
- 1
- 2
- 3
- 4
- 5

At your FIRST visit, what kind of doctor did you see?

- Primary Care Provider
- Psychologist or Counselor
- Heart Doctor
- Pacemaker Doctor
- Lung Doctor
- Liver Doctor
- Kidney Doctor
- Diabetes Doctor
- Surgery Doctor
- Other

Was this doctor's appointment at Emory?

- Yes
- No

What was the reason you had to go to the doctor?

______________________________________

At your SECOND visit, what kind of doctor did you see?

- Primary Care Provider
- Psychologist or Counselor
- Heart Doctor
- Pacemaker Doctor
- Lung Doctor
- Liver Doctor
- Kidney Doctor
- Diabetes Doctor
- Surgery Doctor
- Other

Was this doctor's appointment at Emory?

- Yes
- No

What was the reason you had to go to the doctor?

______________________________________

At your THIRD visit, what kind of doctor did you see?

- Primary Care Provider
- Psychologist or Counselor
- Heart Doctor
- Pacemaker Doctor
- Lung Doctor
- Liver Doctor
- Kidney Doctor
- Diabetes Doctor
- Surgery Doctor
- Other

Was this doctor's appointment at Emory?

- Yes
- No

What was the reason you had to go to the doctor?

______________________________________
At your FOURTH visit, what kind of doctor did you see?

- Primary Care Provider
- Psychologist or Counselor
- Heart Doctor
- Pacemaker Doctor
- Lung Doctor
- Liver Doctor
- Kidney Doctor
- Diabetes Doctor
- Surgery Doctor
- Other

Was this doctor's appointment at Emory?

- Yes
- No

What was the reason you had to go to the doctor?

At your FIFTH visit, what kind of doctor did you see?

- Primary Care Provider
- Psychologist or Counselor
- Heart Doctor
- Pacemaker Doctor
- Lung Doctor
- Liver Doctor
- Kidney Doctor
- Diabetes Doctor
- Surgery Doctor
- Other

Was this doctor's appointment at Emory?

- Yes
- No

What was the reason you had to go to the doctor?
In the past month, how many times did you go to the emergency room?

○ 0
○ 1
○ 2
○ 3

At your FIRST emergency room visit, did you go to the Emory emergency room?

○ Yes
○ No

What was the reason you had to go to the emergency room?

__________________________

List any tests or procedures you had done in the Emergency Room

__________________________

At your SECOND emergency room visit, did you go to the Emergency Room at Emory?

○ Yes
○ No

What was the reason you had to go to the emergency room?

__________________________

List any tests or procedures you had done in the Emergency Room

__________________________

At your THIRD emergency room visit, did you go to the Emergency Room at Emory?

○ Yes
○ No

What was the reason you had to go to the emergency room?

__________________________

List any tests or procedures you had done in the Emergency Room

__________________________
In the past month, how many times were you hospitalized?  
0 1 2 3

At your FIRST hospitalization, did you go to Emory?  Yes  No

How many days were you in the hospital?  

What was the reason you were hospitalized?  

List any tests or procedures you had done in the hospital.  

At your SECOND hospitalization, did you go to Emory?  Yes  No

How many days were you in the hospital?  

What was the reason you were hospitalized?  

List any tests or procedures you had done in the hospital.  

At your THIRD hospitalization, did you go to Emory?  Yes  No

How many days were you in the hospital?  

What was the reason you were hospitalized?  

List any tests or procedures you had done in the hospital.  

### HRU.Validation

HRU Notes:  

Date of Recruitment  

Number of doctor visits.  

Number of cardiology doctor visits.  

Number of non-cardiology doctor visits.  

Number of routine doctor visits.  

Number of non-routine doctor visits.

<table>
<thead>
<tr>
<th>Types of doctors</th>
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<tbody>
<tr>
<td>Primary Care Provider</td>
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<tr>
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<td>Liver Doctor</td>
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<td>Kidney Doctor</td>
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<tr>
<td>Diabetes Doctor</td>
</tr>
<tr>
<td>Surgery Doctor</td>
</tr>
<tr>
<td>Other</td>
</tr>
</tbody>
</table>

Number of emergency room visits  

Reasons for ED visit  

Number of heart-related ED visits  

Number of non-heart related ED visit  

Number of hospitalizations  

Days in hospital  

Reason for hospitalizations  

Number of heart related hospitalizations  

Number of non-heart related hospitalizations
Charlson Comorbidity Index

Comorbidity (Choose all that are present) Assigned weights for each condition the patient has ( )

- Myocardial infarct (+1)
- Congestive heart failure (+1)
- Peripheral vascular disease (+1)
- Cerebrovascular disease (except hemiplegia) (+1)
- Dementia (+1)
- Chronic pulmonary disease (+1)
- Connective tissue disease (+1)
- Ulcer disease (+1)
- Mild liver disease (+1)
- Diabetes (without complications) (+1)
- Diabetes with end organ damage (+2)
- Hemiplegia (+2)
- Moderate or severe renal disease (+2)
- Solid tumor (non metastatic) (+2)
- Leukemia (+2)
- Lymphoma, Multiple myeloma (+2)
- Moderate or severe liver disease (+3)
- Metastatic solid tumor (+6)
- AIDS (+6)

Age

- 50 - 59 (+1)
- 60 - 69 (+2)
- 70 - 79 (+3)
- 80 - 89 (+4)
- 90 - 99 (+5)

List actual comorbidities (may want to use descriptively)

________________________________________

Total points:

________________________________________
New Comorbidity Score

Comorbidity Notes

List actual comorbidities (may want to use descriptively)

Comorbidity (Choose all that are present)

- Myocardial infarct
- Congestive heart failure
- Peripheral vascular disease
- Cerebrovascular disease (except hemiplegia)
- Dementia
- PAH
- Connective tissue disease
- Ulcer disease
- Mild liver disease
- Diabetes (without complications)
- Diabetes with end organ damage
- Hemiplegia
-Moderate or severe renal disease
- Solid tumor (non metastatic)
- Leukemia
- Lymphoma, Multiple myeloma
- Moderate or severe liver disease
-Metastatic solid tumor
- AIDS
- Arrhythmia
- Thyroid Disease
- GERD/Gastritis
- Anxiety
- Depression
- Other mental illness (bipolar, personality disorder, etc)
- Musculoskeletal disorder
- Anemia
- OSA
- Asthma
- COPD
- Dyslipidemia
- Hypertension
- Cholelithiasis
- Gout
- Other
Vital Signs

Date of Vital Signs

Height (cm)

Weight (kilograms)

BMI

Systolic BP

Diastolic BP

Heart Rate

Oxygen Saturation

NYHA Class

☐ I
☐ II
☐ III
☐ IV
Sc Validation Items

Annual flu shot 2013-2014

Number of Cardiology office visits in past year.
Number of hospitalizations in past year.
Number of ED visits in past year.
## Medication List

Please indicate all other medications by generic name, dose and frequency.

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<thead>
<tr>
<th>Medication 1</th>
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<tr>
<td>Medication 1 unit</td>
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<td></td>
</tr>
<tr>
<td>☐ g</td>
<td>☐ mg</td>
<td>☐ mcg</td>
</tr>
<tr>
<td>☐ mL</td>
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<td>☐ units</td>
</tr>
<tr>
<td>☐ other</td>
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<td>☐ tid</td>
</tr>
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<td>☐ q4-6 hrs</td>
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<td>☐ ARB</td>
<td>☐ Beta-blocker</td>
</tr>
<tr>
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<td>☐ Hydralazine</td>
<td>☐ Nitrate</td>
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<tr>
<td>☐ Diuretic</td>
<td>☐ Anticoagulant</td>
<td>☐ Pulmonary vasodilator</td>
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<tr>
<td>☐ Anti-anxiety</td>
<td>☐ Lipid-lowering</td>
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<td>☐ mg</td>
<td>☐ mcg</td>
</tr>
<tr>
<td>☐ mL</td>
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<td>☐ units</td>
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<td>☐ tid</td>
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<td>☐ prn</td>
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Class of Drug

- ACE Inhibitor
- ARB
- Beta-blocker
- Anti-arrhythmic
- Hydralazine
- Nitrates
- Diuretic
- Anticoagulant
- Pulmonary vasodilator
- Anti-anxiety
- Lipid-lowering
- Analgesic
- NSAID
- Herbal supplement
- Other

Medication 3

Medication 3 dose

Medication 3 unit

- g
- mg
- mcg
- mL
- drops/puffs
- units
- other

Medication 4

Medication 4 dose

Medication 4 unit

- g
- mg
- mcg
- mL
- drops/puffs
- units
- other
| Medation 4 frequency | ○ qd  
|                     | ○ bid  
|                     | ○ tid  
|                     | ○ qid  
|                     | ○ q4-6 hrs  
|                     | ○ prn  
|                     | ○ Unknown  
| Class of Drug | ○ ACE Inhibitor  
|                | ○ ARB  
|                | ○ Beta-blocker  
|                | ○ Anti-arrhythmic  
|                | ○ Hydralazine  
|                | ○ Nitrate  
|                | ○ Diuretic  
|                | ○ Anticoagulant  
|                | ○ Pulmonary vasodilator  
|                | ○ Anti-anxiety  
|                | ○ Lipid-lowering  
|                | ○ Analgesic  
|                | ○ NSAID  
|                | ○ Herbal supplement  
|                | ○ Other  
| Medication 5 |  
| Medication 5 dose |  
| Medication 5 unit | ○ g  
|                   | ○ mg  
|                   | ○ mcg  
|                   | ○ mL  
|                   | ○ drops/puffs  
|                   | ○ units  
|                   | ○ other  
| Medation 5 frequency | ○ qd  
|                         | ○ bid  
|                         | ○ tid  
|                         | ○ qid  
|                         | ○ q4-6 hrs  
|                         | ○ prn  
|                         | ○ Unknown  
| Class of Drug | ○ ACE Inhibitor  
|                | ○ ARB  
|                | ○ Beta-blocker  
|                | ○ Anti-arrhythmic  
|                | ○ Hydralazine  
|                | ○ Nitrate  
|                | ○ Diuretic  
|                | ○ Anticoagulant  
|                | ○ Pulmonary vasodilator  
|                | ○ Anti-anxiety  
|                | ○ Lipid-lowering  
|                | ○ Analgesic  
|                | ○ NSAID  
|                | ○ Herbal supplement  
|                | ○ Other  
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| Medication 6 dose |<br />
| Medication 5 dose |</p>
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<td>q4-6 hrs</td>
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<tr>
<td>Anti-anxiety</td>
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</table>

| Medication 8                  |                          |                          |                          |                          |                          |                          |                          |                          |
| Medication 8 dose             |                          |                          |                          |                          |                          |                          |                          |                          |
| Medication 8 unit             | g                        | mg                       | mcg                      | mL                       | drops/puffs              | units                    | other                    |                          |

| Mediation 8 frequency         | qd                       | bid                      | tid                      | qid                      | q4-6 hrs                 | prn                      | Unknown                  |                          |

| Class of Drug                 |                          |                          |                          |                          |                          |                          |                          |                          |
| ACE Inhibitor                 | ARB                      | Beta-blocker             | Anti-arrhythmic          | Hydralazine              | Nitrate                  | Diuretic                 | Anticoagulant            | Pulmonary vasodilator     |
| Anti-anxiety                  | Lipid-lowering           | Analgesic                | NSAID                    | Herbal supplement        | Other                    |                          |                          |                          |

| Medication 9                  |                          |                          |                          |                          |                          |                          |                          |                          |
| Medication 9 dose             |                          |                          |                          |                          |                          |                          |                          |                          |
| Medication 9 unit             | g                        | mg                       | mcg                      | mL                       | drops/puffs              | units                    | other                    |                          |
Medication 9 frequency
- qd
- bid
- tid
- qid
- q4-6 hrs
- prn
- Unknown

Class of Drug
- ACE Inhibitor
- ARB
- Beta-blocker
- Anti-arrhythmic
- Hydralazine
- Nitrate
- Diuretic
- Anticoagulant
- Pulmonary vasodilator
- Anti-anxiety
- Lipid-lowering
- Analgesic
- NSAID
- Herbal supplement
- Other

Medication 10

Medication 10 dose

Medication 10 unit
- g
- mg
- mcg
- mL
- drops/puffs
- units
- other

Medation 10 frequency
- qd
- bid
- tid
- qid
- q4-6 hrs
- prn
- Unknown

Class of Drug
- ACE Inhibitor
- ARB
- Beta-blocker
- Anti-arrhythmic
- Hydralazine
- Nitrate
- Diuretic
- Anticoagulant
- Pulmonary vasodilator
- Anti-anxiety
- Lipid-lowering
- Analgesic
- NSAID
- Herbal supplement
- Other

Medication 11

Medication 11 dose
<table>
<thead>
<tr>
<th>Medication 11 unit</th>
<th>g</th>
<th>mg</th>
<th>mcg</th>
<th>mL</th>
<th>drops/puffs</th>
<th>units</th>
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<tbody>
<tr>
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<td>qd</td>
<td>bid</td>
<td>tid</td>
<td>qid</td>
<td>q4-6 hrs</td>
<td>prn</td>
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<tr>
<td>Class of Drug</td>
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<td>ARB</td>
<td>Beta-blocker</td>
<td>Anti-arrhythmic</td>
<td>Hydralazine</td>
<td>Nitrates</td>
<td>Diuretic</td>
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<tr>
<td>Medication 12</td>
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<td></td>
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<tr>
<td>Medication 12 unit</td>
<td>g</td>
<td>mg</td>
<td>mcg</td>
<td>mL</td>
<td>drops/puffs</td>
<td>units</td>
<td>other</td>
</tr>
<tr>
<td>Medication 12 frequency</td>
<td>qd</td>
<td>bid</td>
<td>tid</td>
<td>qid</td>
<td>q4-6 hrs</td>
<td>prn</td>
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<td>Class of Drug</td>
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<td>ARB</td>
<td>Beta-blocker</td>
<td>Anti-arrhythmic</td>
<td>Hydralazine</td>
<td>Nitrate</td>
<td>Diuretic</td>
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<td>Medication 13</td>
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<tr>
<td>Medication 13 dose</td>
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</tr>
<tr>
<td>Medication 13 unit</td>
<td>g</td>
<td>mg</td>
<td>mcg</td>
<td>mL</td>
<td>drops/puffs</td>
<td>units</td>
<td>other</td>
</tr>
<tr>
<td>Medation 13 frequency</td>
<td>qd</td>
<td>bid</td>
<td>tid</td>
<td>qid</td>
<td>q4-6 hrs</td>
<td>prn</td>
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<td>Class of Drug</td>
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<td>ARB</td>
<td>Beta-blocker</td>
<td>Anti-arrhythmic</td>
<td>Hydralazine</td>
<td>Nitrate</td>
<td>Diuretic</td>
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<td>Medication 14</td>
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<td></td>
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</tr>
<tr>
<td>Medication 14 unit</td>
<td>g</td>
<td>mg</td>
<td>mcg</td>
<td>mL</td>
<td>drops/puffs</td>
<td>units</td>
<td>other</td>
</tr>
<tr>
<td>Medication 14 frequency</td>
<td>qd</td>
<td>bid</td>
<td>tid</td>
<td>qid</td>
<td>q4-6 hrs</td>
<td>prn</td>
<td>Unknown</td>
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<tr>
<td>Class of Drug</td>
<td>ACE Inhibitor</td>
<td>ARB</td>
<td>Beta-blocker</td>
<td>Anti-arrhythmic</td>
<td>Hydralazine</td>
<td>Nitrate</td>
<td>Diuretic</td>
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<tr>
<td>Medication 15</td>
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<tr>
<td>Medication 15 dose</td>
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<tr>
<td>Medication 15 unit</td>
<td>g</td>
<td>mg</td>
<td>mcg</td>
<td>mL</td>
<td>drops/puffs</td>
<td>units</td>
<td>other</td>
</tr>
<tr>
<td>Medication 15 frequency</td>
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<td>Beta-blocker</td>
<td>Anti-arrhythmic</td>
<td>Hydralazine</td>
<td>Nitrate</td>
<td>Diuretic</td>
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<tr>
<td>Medication 16</td>
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05/08/2015 3:01pm

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<tr>
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<th>mg</th>
<th>mcg</th>
<th>mL</th>
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<th>units</th>
<th>other</th>
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<td>tid</td>
<td>qid</td>
<td>q4-6 hrs</td>
<td>prn</td>
<td>Unknown</td>
</tr>
<tr>
<td>Class of Drug</td>
<td>ACE Inhibitor</td>
<td>ARB</td>
<td>Beta-blocker</td>
<td>Anti-arrhythmic</td>
<td>Hydralazine</td>
<td>Nitrates</td>
<td>Diuretic</td>
</tr>
<tr>
<td>Medication 17</td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>Medication 17 dose</td>
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</tr>
<tr>
<td>Medication 17 unit</td>
<td>g</td>
<td>mg</td>
<td>mcg</td>
<td>mL</td>
<td>drops/puffs</td>
<td>units</td>
<td>other</td>
</tr>
<tr>
<td>Medation 17 frequency</td>
<td>qd</td>
<td>bid</td>
<td>tid</td>
<td>qid</td>
<td>q4-6 hrs</td>
<td>prn</td>
<td>Unknown</td>
</tr>
</tbody>
</table>
Class of Drug

ACE Inhibitor
ARB
Beta-blocker
Anti-arrhythmic
Hydralazine
Nitrate
Diuretic
Anticoagulant
Pulmonary vasodilator
Anti-anxiety
Lipid-lowering
Analgesic
NSAID
Herbal supplement
Other

Medication 18

Medication 18 dose

Medication 18 unit

Medication 18 frequency

qd
bid
tid
qid
q4-6 hrs
prn
Unknown

Class of Drug

ACE Inhibitor
ARB
Beta-blocker
Anti-arrhythmic
Hydralazine
Nitrate
Diuretic
Anticoagulant
Pulmonary vasodilator
Anti-anxiety
Lipid-lowering
Analgesic
NSAID
Herbal supplement
Other

Medication 19

Medication 19 dose

Medication 19 unit
Medication 19 frequency

- qd
- bid
- tid
- qid
- q4-6 hrs
- prn
- Unknown

Class of Drug

- ACE Inhibitor
- ARB
- Beta-blocker
- Anti-arrhythmic
- Hydralazine
- Nitrate
- Diuretic
- Anticoagulant
- Pulmonary vasodilator
- Anti-anxiety
- Lipid-lowering
- Analgesic
- NSAID
- Herbal supplement
- Other

Total # daily meds

----------------------------------------
## Labs

### Systemic Ventricle

- Left
- Right

### Systemic Ventricular Dysfunction

- none
- mild
- moderate
- severe

### Ejection Fraction

- ________________

### K

- __________________

### Na

- __________________

### Cl

- __________________

### CO2

- __________________

### Glucose

- __________________

### BUN

- __________________

### Cr

- __________________

### Albumin

- __________________

### Ca

- __________________

### WBC

- __________________

### Hgb

- __________________

### Hct

- __________________
Six Minute Walk Test

6-Minute Walk Test Date

Reasons for Test NOT Performed

- [ ] Test was done
- [ ] Patient Declined
- [ ] Disability (mental, physical)
- [ ] Medical (illness, gout, chest pain, etc)
- [ ] Technical

Did the patient use oxygen during the 6MWT?

- [ ] Yes
- [ ] No

Resting Vital Signs

Systolic BP: _____________________________

Diastolic BP: _____________________________

HR: _____________________________

RR: _____________________________

SpO2 (%): _____________________________

BORG Scale-Baseline

- [ ] No effort
- [ ] very very light
- [ ] 8
- [ ] very light
- [ ] 10
- [ ] fairly light
- [ ] 12
- [ ] somewhat hard
- [ ] 14
- [ ] hard
- [ ] 16
- [ ] very hard
- [ ] 18
- [ ] very very hard
- [ ] maximum

The Test

Time Started: _____________________________

Time Stopped: _____________________________

Total Time Walked (minutes) _____________________________

Total distance walked in feet: _____________________________

Total distance walked (meters) _____________________________

Did participant stop during 6MWT?

- [ ] No
- [ ] Yes

Stop Duration _____________________________

(minutes)
Symptoms during 6MWT:
- Chest Pain
- Syncope
- Lightheadedness
- Staggering
- Muscle Fatigue
- Intolerable Dyspnea
- Leg Cramps
- Pale/ashen appearance
- Diaphoresis
- None

Highest HR

Lowest SpO2 (%)

### Post Vital Signs

Systolic BP:

Diastolic BP:

HR:

RR:

SpO2 (%)

BORG Scale-Maximal
- No effort
- very very light
- 8
- very light
- 10
- fairly light
- 12
- somewhat hard
- 14
- hard
- 16
- very hard
- 18
- very very hard
- maximum

### 2 Min Post Vital Signs

Systolic BP:

Diastolic BP:

HR:

RR:

SpO2 (%)

Six minutes walk test notes
Please complete the survey below.

Thank you!

---

**Over the LAST 2 WEEKS, how often have you been bothered by the following problems?**

<table>
<thead>
<tr>
<th>Item</th>
<th>Not at all</th>
<th>Several days</th>
<th>More than half the days</th>
<th>Nearly every day</th>
</tr>
</thead>
<tbody>
<tr>
<td>570) Feeling nervous, anxious or on edge</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>571) Not being able to stop or control worrying</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>572) Worrying too much about different things</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>573) Trouble relaxing</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>574) Being so restless that it is hard to sit still</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>575) Becoming easily annoyed or irritable</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>576) Feeling afraid as if something awful might happen</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
## Knowledge Validation

What is the name of your heart defect?

<table>
<thead>
<tr>
<th>Points_Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>incorrect</td>
</tr>
<tr>
<td>partially correct</td>
</tr>
<tr>
<td>correct</td>
</tr>
</tbody>
</table>

How many heart surgeries have you had?

<table>
<thead>
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<th>Points_Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
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</tr>
<tr>
<td>2</td>
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<td>4</td>
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<tr>
<td>5</td>
</tr>
<tr>
<td>More than 5</td>
</tr>
<tr>
<td>incorrect</td>
</tr>
<tr>
<td>partially correct</td>
</tr>
<tr>
<td>correct</td>
</tr>
</tbody>
</table>

List all of the heart surgeries you have had

<table>
<thead>
<tr>
<th>Points_Name</th>
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</thead>
<tbody>
<tr>
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</tr>
<tr>
<td>partially correct</td>
</tr>
<tr>
<td>correct</td>
</tr>
</tbody>
</table>

Do you have any medical conditions other than your heart defect?

<table>
<thead>
<tr>
<th>Points_Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td>incorrect</td>
</tr>
<tr>
<td>partially correct</td>
</tr>
<tr>
<td>correct</td>
</tr>
</tbody>
</table>

List your other medical conditions.

<table>
<thead>
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</thead>
<tbody>
<tr>
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<tr>
<td>partially correct</td>
</tr>
<tr>
<td>correct</td>
</tr>
</tbody>
</table>

Please list your current medications and dosages.

<table>
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</tr>
</thead>
<tbody>
<tr>
<td>incorrect</td>
</tr>
<tr>
<td>partially correct</td>
</tr>
<tr>
<td>correct</td>
</tr>
</tbody>
</table>

What is your current exercise recommendation? (Check all that apply)

<table>
<thead>
<tr>
<th>Points_Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>No restrictions</td>
</tr>
<tr>
<td>Avoid contact sports (such as football or hockey).</td>
</tr>
<tr>
<td>Gentle exercise only (such as walking).</td>
</tr>
<tr>
<td>Avoid competitive sports</td>
</tr>
<tr>
<td>Avoid heavy lifting (weight that makes you strain or get red in the face).</td>
</tr>
<tr>
<td>incorrect</td>
</tr>
<tr>
<td>partially correct</td>
</tr>
<tr>
<td>correct</td>
</tr>
</tbody>
</table>
Check all special precautions that apply to you.

- Flu shot recommended
- Avoid metal detectors
- Supplemental oxygen for air travel recommended
- Avoid traveling to high elevations (>5,000 feet)
- Take antibiotics prior to dental procedures
- Notify my providers to take blood pressure in only one arm. My pressure is lower in one arm than in the other because of a prior surgery.
- Eat a low-salt diet (< 2,000 mg per day)
- Always use air filters when getting IV fluids or medications

Points_Name

- ○ incorrect
- ○ partially correct
- ○ correct

Do you have an advance directive?

- ○ Yes
- ○ No

Points_Name

- ○ incorrect
- ○ partially correct
- ○ correct

Are you a woman?

- ○ Yes
- ○ No

What is your current pregnancy recommendation?

- ○ Pregnancy not currently recommended because of risk to me and my baby.
- ○ Consultation with my heart doctor prior to becoming pregnant.
- ○ Planned pregnancy under direct supervision of my heart doctor.
- ○ No restrictions. My risk is the same as for women without a heart defect.

Points_Name

- ○ incorrect
- ○ partially correct
- ○ correct

What is your current contraception recommendation?

- ○ Progestin only
- ○ Low dose estrogen/progestin
- ○ Barrier method (such as condoms or diaphragms)
- ○ IUD (such as paraguard, marina)
- ○ No special recommendations. My risks are the same as a women without a heart defect.
- ○ Not applicable (hysterectomy, tubal ligation, or menopause)

Points_Name

- ○ incorrect
- ○ partially correct
- ○ correct

Notes:

________________________________________________________________________

Total Score

________________________________________________________________________

______________________________
## Knowledge Score

Yes/No refers to whether or not the subject answered the question CORRECTLY. Yes, answered correctly. No, did not answer correctly.

<table>
<thead>
<tr>
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<tr>
<td>Other Conditions</td>
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<td>Name Other Conditions</td>
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<tr>
<td>Medications</td>
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<tr>
<td>Exercise: No restrictions</td>
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<td></td>
</tr>
<tr>
<td>Exercise: no contact sports</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Exercise: Gentle only</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Exercise: no competitive sports</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Exercise: No heavy lifting</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Special Precautions (SP): flu shot</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SP: no metal detectors</td>
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<td></td>
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<tr>
<td>SP: travel with oxygen</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SP: avoid high elevation</td>
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<td></td>
</tr>
<tr>
<td>SP: antibiotics prior to dental</td>
<td></td>
<td></td>
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<td>SP: BP one arm</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SP: low salt diet</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SP: air filters on IV lines</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Advance Directives

- Yes
- No

Pregnancy Recommendation

- Yes
- No

Contraception Recommendation

- Yes
- No
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Expected completion date Aug 2015
Estimated size(pages) 200
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1331 E Rock Springs Rd NE

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United States
Attn: Nancy McCabe

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Billing Address Nancy McCabe
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<table>
<thead>
<tr>
<th>Study</th>
<th>N</th>
<th>Mean Age</th>
<th>ACCD Type or Severity</th>
<th>Age</th>
<th>Physical Activity</th>
<th>Antecedents</th>
<th>Outcomes</th>
<th>Adequacy</th>
<th>ACCHD Type or Severity</th>
<th>Study</th>
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<tbody>
<tr>
<td>van der Bom et al (2015)</td>
<td>48</td>
<td>29</td>
<td>TGA (Mustard repair)</td>
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<td></td>
<td>n/a</td>
<td></td>
<td>50%</td>
<td></td>
<td></td>
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<td>59</td>
<td>24</td>
<td>Single Ventricle</td>
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<td></td>
<td>n/a</td>
<td></td>
<td>39%</td>
<td></td>
<td></td>
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<td>Buys et al (2014)</td>
<td>87</td>
<td>27</td>
<td>TOF</td>
<td></td>
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<td>n/a</td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>Buys et al (2013)</td>
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<td>34</td>
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<td>n/a</td>
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<td>TGA</td>
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<td>n/a</td>
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<tr>
<td>Ubeda-Tikkanen et al (2013)</td>
<td>103</td>
<td>29</td>
<td>TGA</td>
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<td>n/a</td>
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**Table 2.4. Literature Synthesis Supplemental Table**
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<th>Antecedents</th>
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<td>Cordina et al (2013)</td>
<td>11</td>
<td>32</td>
<td>Fontan</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
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<tr>
<td>Becker-Grunig et al (2013)</td>
<td>20</td>
<td>NR</td>
<td>Other</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
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<tr>
<td>Muller et al (2010)</td>
<td>330</td>
<td>18-61</td>
<td>Fontan/TGA/TOF</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
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<tr>
<td>Dua et al (2010)</td>
<td>61</td>
<td>32</td>
<td>Gender differences</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
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<tr>
<td>Winter et al (2008)</td>
<td>47</td>
<td>35</td>
<td>Cohort</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
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</tbody>
</table>

**Relevant Information**

- **Improvement:**
  - Resistance training improves exercise capacity (peak oxygen uptake) and hemodynamic parameters.
  - Exercise training improves exercise capacity (peak oxygen uptake and maximal workload) and QOL.

- **Recommendations:**
  - Not related to type of heart defect after adjusting for age; men had higher rates of daily activity; daily activity decreased with age.
  - Moderate relationship between daily activity and exercise capacity (r=.44), but not with QOL (r=.03).
<table>
<thead>
<tr>
<th>Study</th>
<th>N</th>
<th>Mean Age</th>
<th>ACHD Type or Severity</th>
<th>Antecedents</th>
<th>Outcomes</th>
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<tbody>
<tr>
<td>De Belser et al (2013)</td>
<td>153</td>
<td>21-27</td>
<td>44% Moderate</td>
<td>Majority had physical activity levels adequate for less than half of patients</td>
<td>Physical activity levels decreased with age (r=−.38)</td>
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<td></td>
<td></td>
<td></td>
<td>46% Moderate</td>
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<td></td>
<td></td>
<td></td>
<td>18% Moderate</td>
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<td></td>
<td></td>
<td></td>
<td>44% Sever</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>56% Moderate</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dua et al (2007)</td>
<td>61</td>
<td>32</td>
<td></td>
<td>Lower physical activity with higher NYHA Class I/II/III respectively did not meet physical activity recommendations</td>
<td>Physical activity levels decreased with age (r=−.38)</td>
</tr>
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<td></td>
<td></td>
<td></td>
<td>77%, 84%, and 100%</td>
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<td></td>
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<tr>
<td>Wray et al (2013)</td>
<td>216</td>
<td>32</td>
<td>TOF</td>
<td>Lack of knowledge of specialty care availability</td>
<td>Lay lost to follow-up, no complications except for less than half of patients</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>30% Simple</td>
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<tr>
<td>Norris et al (2013)</td>
<td>135</td>
<td>24</td>
<td></td>
<td>Majority had physical activity levels adequate for less than half of patients</td>
<td>D-TGA (Mustard/Senning)</td>
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<td></td>
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<td></td>
<td>56% Moderate</td>
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<td></td>
<td>44% Moderate</td>
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<td></td>
<td>18% Moderate</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>44% Sever</td>
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<td></td>
<td></td>
<td>56% Moderate</td>
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</table>

**Routine Follow-Up**

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<th>Study</th>
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<th>ACHD Type or Severity</th>
<th>Antecedents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dua et al (2007)</td>
<td>61</td>
<td>32</td>
<td></td>
<td>Relayed activities in sports-controls except for less than half of patients</td>
</tr>
<tr>
<td></td>
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<td></td>
</tr>
<tr>
<td>De Belser et al</td>
<td>42</td>
<td>70</td>
<td></td>
<td>Majority had physical activity levels adequate for less than half of patients</td>
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**Study**
<table>
<thead>
<tr>
<th>Study</th>
<th>N</th>
<th>Mean Age</th>
<th>ACHD Type or Severity</th>
<th>Antecedents</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gurvitz et al (2013)</td>
<td>643</td>
<td>22</td>
<td>13% Severe</td>
<td>922</td>
<td>20</td>
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<tr>
<td>Goossens et al (2011)</td>
<td>593</td>
<td>40</td>
<td>14% Moderate</td>
<td>794</td>
<td>18-22</td>
</tr>
<tr>
<td>Vis et al (2011)</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>100% of adults in study were lost to follow-up, 7% of patients lost to follow-up, 76% had new cardiac findings</td>
</tr>
<tr>
<td>Mackie et al (2009)</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>61% Simple, 26% Other, 13% Severe</td>
</tr>
</tbody>
</table>

Feeling well, lack of knowledge of follow-up needs, and complete absence of medical care most commonly self-reported reasons for gaps in care. Disease complexity and clinic location significantly predicted gaps in care, but not gender, age, or education level. Male sex, non-severe CHD, history of follow-up outside of an academic healthcare system more likely to be lost to follow-up.
<table>
<thead>
<tr>
<th>Study</th>
<th>N</th>
<th>Substance Use</th>
<th>Outcomes</th>
<th>Antecedents</th>
<th>Adequacy</th>
<th>Severity of ACCHD Type or Diagnosis</th>
<th>Mean Age</th>
<th>N</th>
<th>Study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yeung et al (2008)</td>
<td>158</td>
<td></td>
<td></td>
<td>Lapses in care greater than 3 years are associated with 3 years of previous substance use.</td>
<td></td>
<td>70%</td>
<td>158</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Zomer et al (2012)</td>
<td>46</td>
<td>Substance use</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Reid et al (2008)</td>
<td>19</td>
<td></td>
<td></td>
<td>Lapses in care greater than 3 years associated with 5 times the odds of being symptomatic at presentation, 12 times more likely to have a new diagnosis, and 3 times more likely to need an urgent intervention.</td>
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<tr>
<td>Study</td>
<td>N</td>
<td>Age Adequacy</td>
<td>Antecedents</td>
<td>Outcomes</td>
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<tr>
<td>Overgaard et al (2014)</td>
<td>59</td>
<td>NR</td>
<td>NR</td>
<td>20% no dental visit in past year</td>
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<tr>
<td>NR</td>
<td>NR</td>
<td>Only 15% saw a dentist</td>
<td>Single Ventricle</td>
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<tr>
<td>Engelfriet et al (2008)</td>
<td>3375</td>
<td>9.3% current smokers, 4.2% past smokers</td>
<td>Men more likely to be current smokers and differences by defect type; no difference by age</td>
<td>TGA, Fontan, Cyanotic</td>
<td></td>
<td></td>
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</tbody>
</table>
| Reid et al (2008)             | 197 | 4% of men and 15% of women reported smoking | Regularly tobacco use is more likely | Endocarditis Prevention
| NR                            | NR  | 23% of CHD non-operated, 7% CHD operated, 35% palliated, 39% corrected | Only 15% saw a dentist | Single Ventricle |
| Overgaard et al (2014)        | 153 | 20% of men and 15% of women reported smoking | Currently abusers of drugs and % drink ≥1x/month, % binge drink ≥1x/month, 20% currently smoke, | Single Ventricle |

Note: NR = Not Reported

Overgaard et al. (2014) Study

Endocarditis Prevention

Smoking-related mortality (HR=4.2)
<table>
<thead>
<tr>
<th>Study</th>
<th>N</th>
<th>Mean Age</th>
<th>ACHD Type or Severity Adequacy</th>
<th>Antecedents</th>
<th>Outcomes</th>
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</thead>
<tbody>
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<td>Knirsch et al (2005)</td>
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<td>NR</td>
<td>NR</td>
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<td>25% of cases related to dental procedures without antibiotic prophylaxis</td>
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<td>75% of cases related to dental procedures</td>
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<td></td>
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<td></td>
<td>33% of dentists</td>
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<td>Niwa et al (2005)</td>
<td>NR</td>
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<td>Pemberton et al (2011)</td>
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<td>Zaidi et al (2013)</td>
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<tr>
<td>obesity is a modifiable risk factor associated with worsened biventricular function and biventricular systolic dysfunction; no differences with normative population; significant differences by CHD severity</td>
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<td>Pemberton et al (2008)</td>
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<td>Moons et al (2009)</td>
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*NR=Not Reported*