Moving from Pediatric to Adult-Oriented Care: A Framework for Successful Transition

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10 million children with "special health care needs"

- Congenital heart disease
  - >2.5 million patients in U.S.
- Cystic fibrosis
  - 30,000 patients in U.S
- Childhood cancer
- Organ transplantation
- Hematologic disorders
  - Sickle cell disease
  - Hemophilia
  - Thalassemia
- Endocrine disorders
  - Diabetes:
    - 3 million patients in U.S.
  - Juvenile rheumatoid arthritis
- Genetic disorders
- Inflammatory bowel disease
  - Crohn's disease
  - Ulcerative colitis

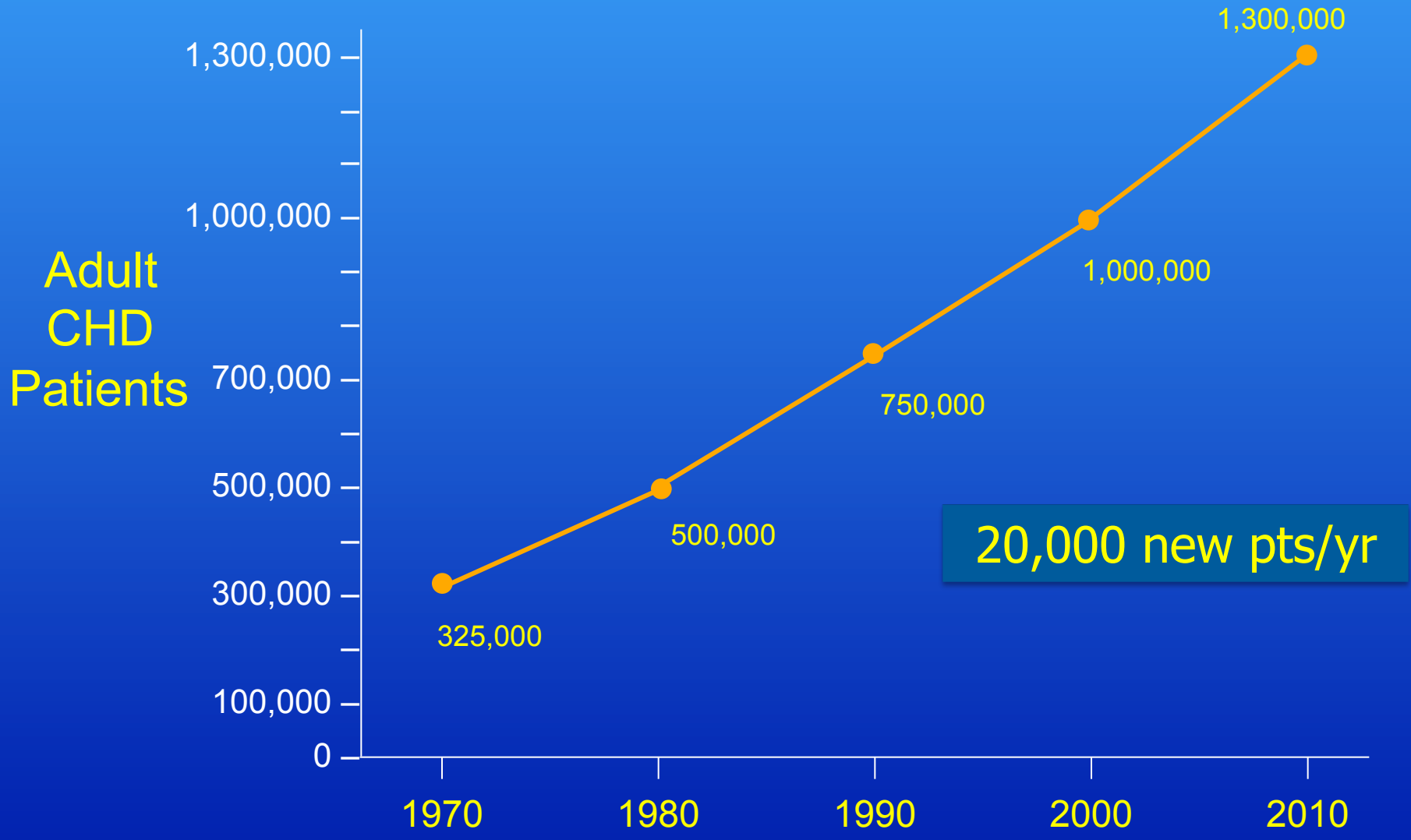
Children with “special health care needs” represent 14% of the population of children yet they account for more than 40% of all health care expenditures for children

Sable et al. 2011; Reiss et al. 2008

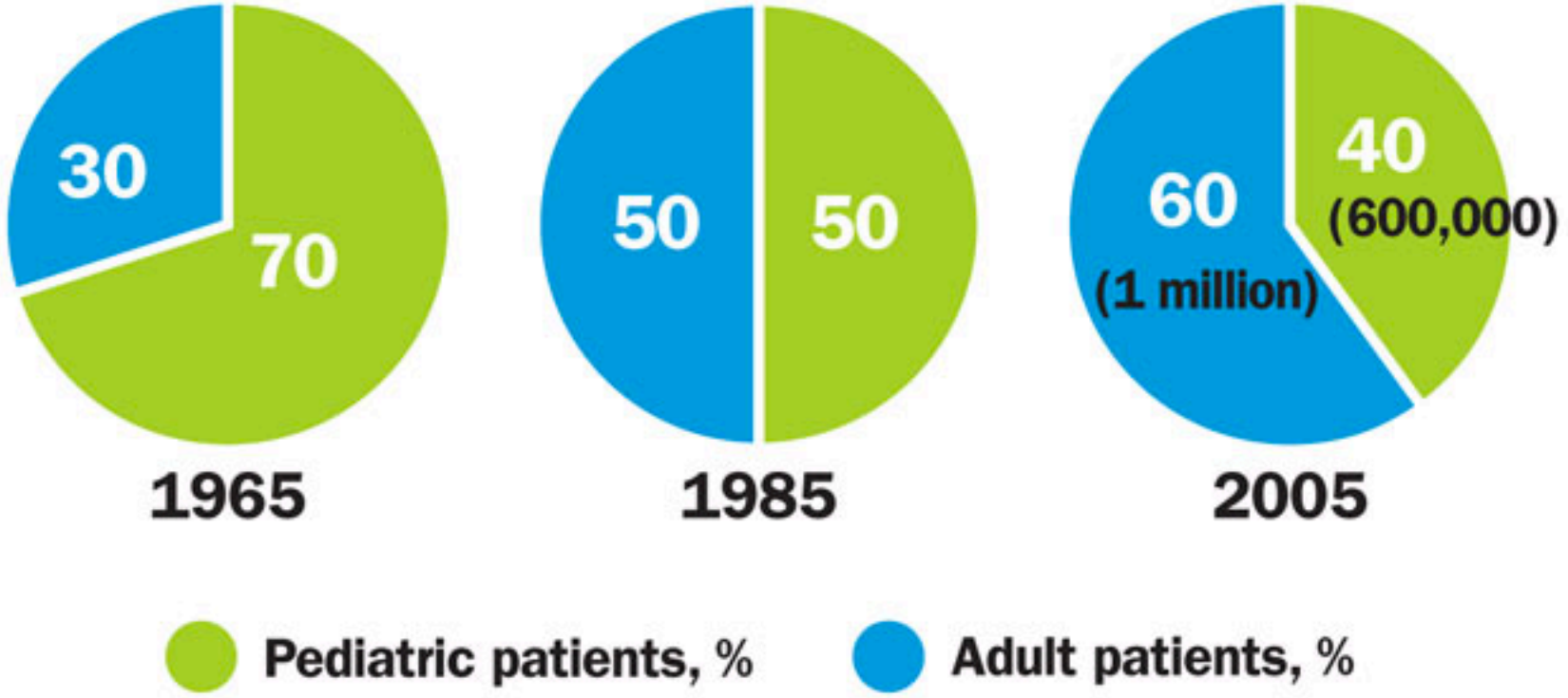
Due to the advancements in surgical and medical management of patients with pediatric onset disease, the overwhelming majority (**>90%**) are expected to live well into adulthood.

Reiss et al 2008

ACHD Population

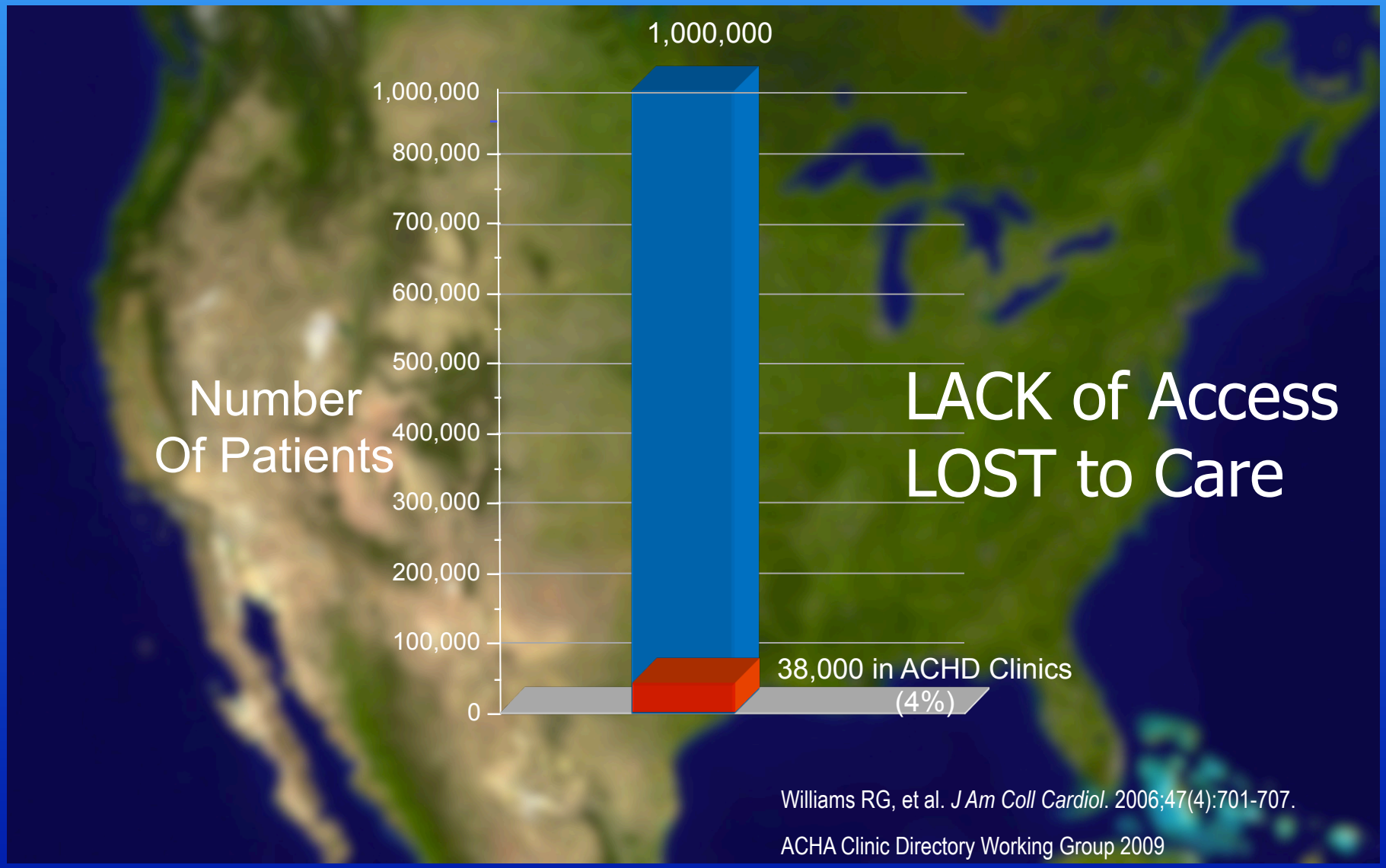


Changing Proportion of Pediatric & Adult CHD



Adapted from: Williams RG, et al. Report of the National Heart, Lung, and Blood Institute Working Group on Research in Adult Congenital Heart Disease. J Am Coll Cardiol. *2006;47(4):701-707.*

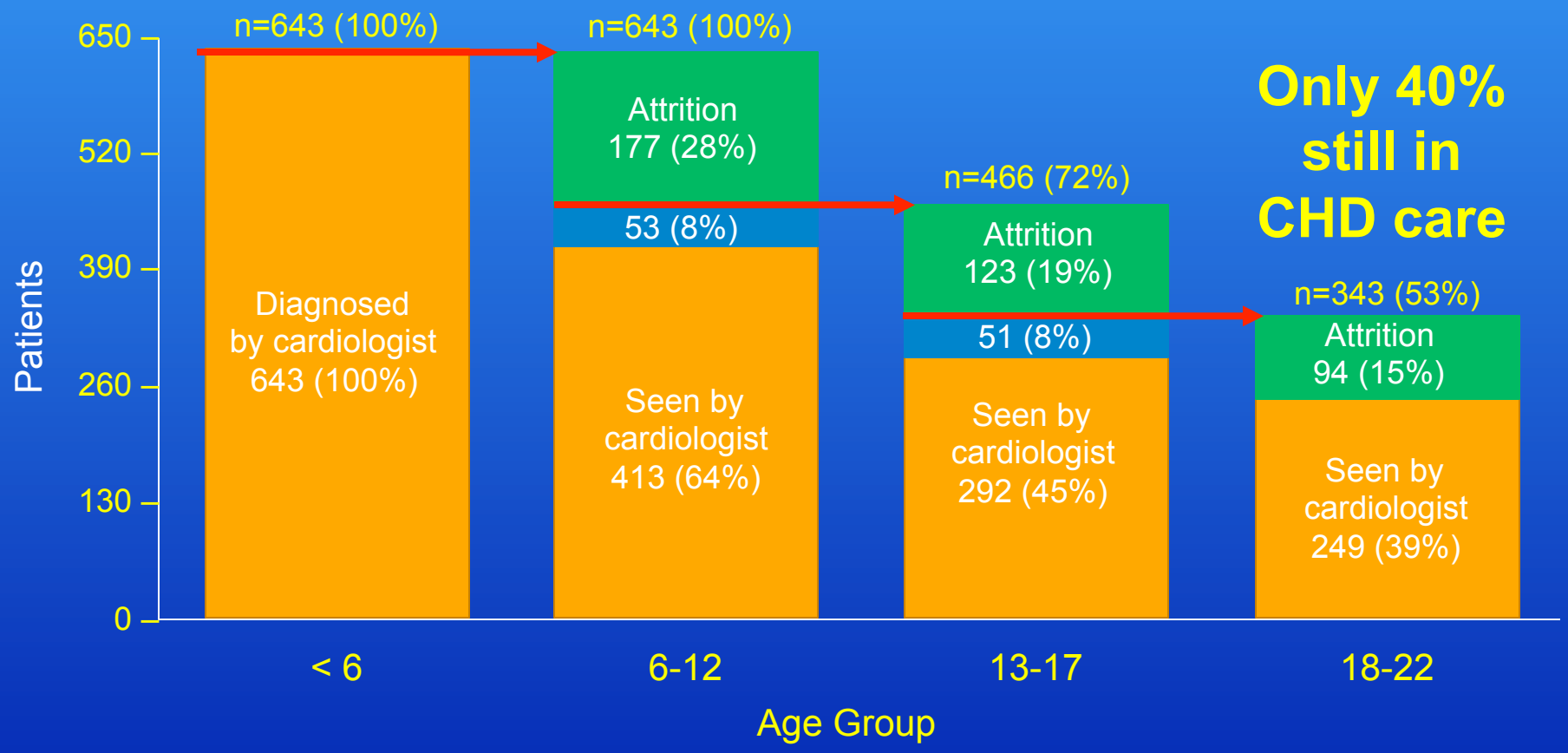
ACHD Patients in U.S. vs Those in ACHD Clinics



Williams RG, et al. *J Am Coll Cardiol*. 2006;47(4):701-707.

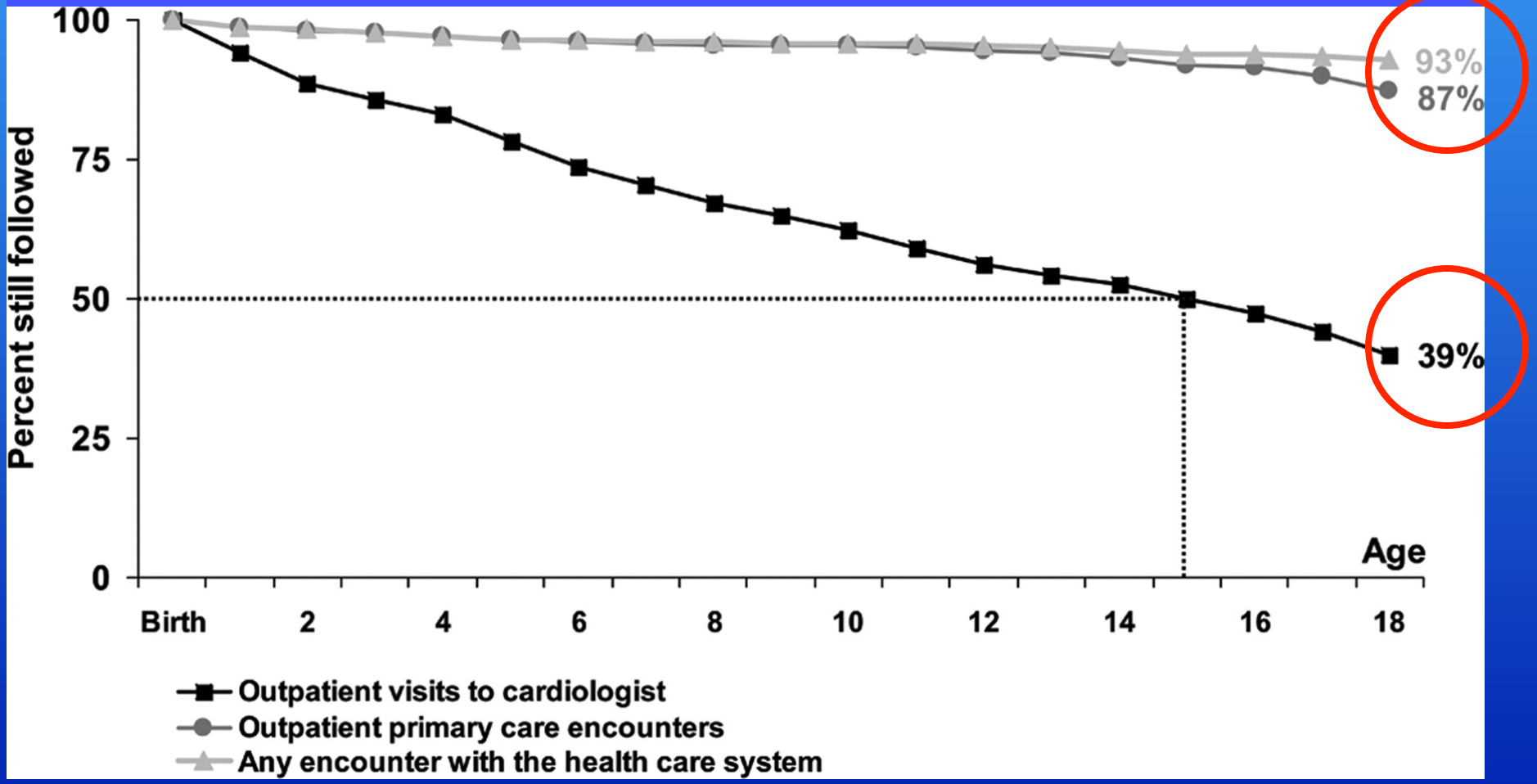
ACHA Clinic Directory Working Group 2009

Children and adults with congenital heart disease lost to follow-up



Mackie, et al. *Circulation.* 2009;120:302-309.

Children and adults with congenital heart disease lost to follow-up



Mackie A S et al. Circulation. 2009;120:302-309

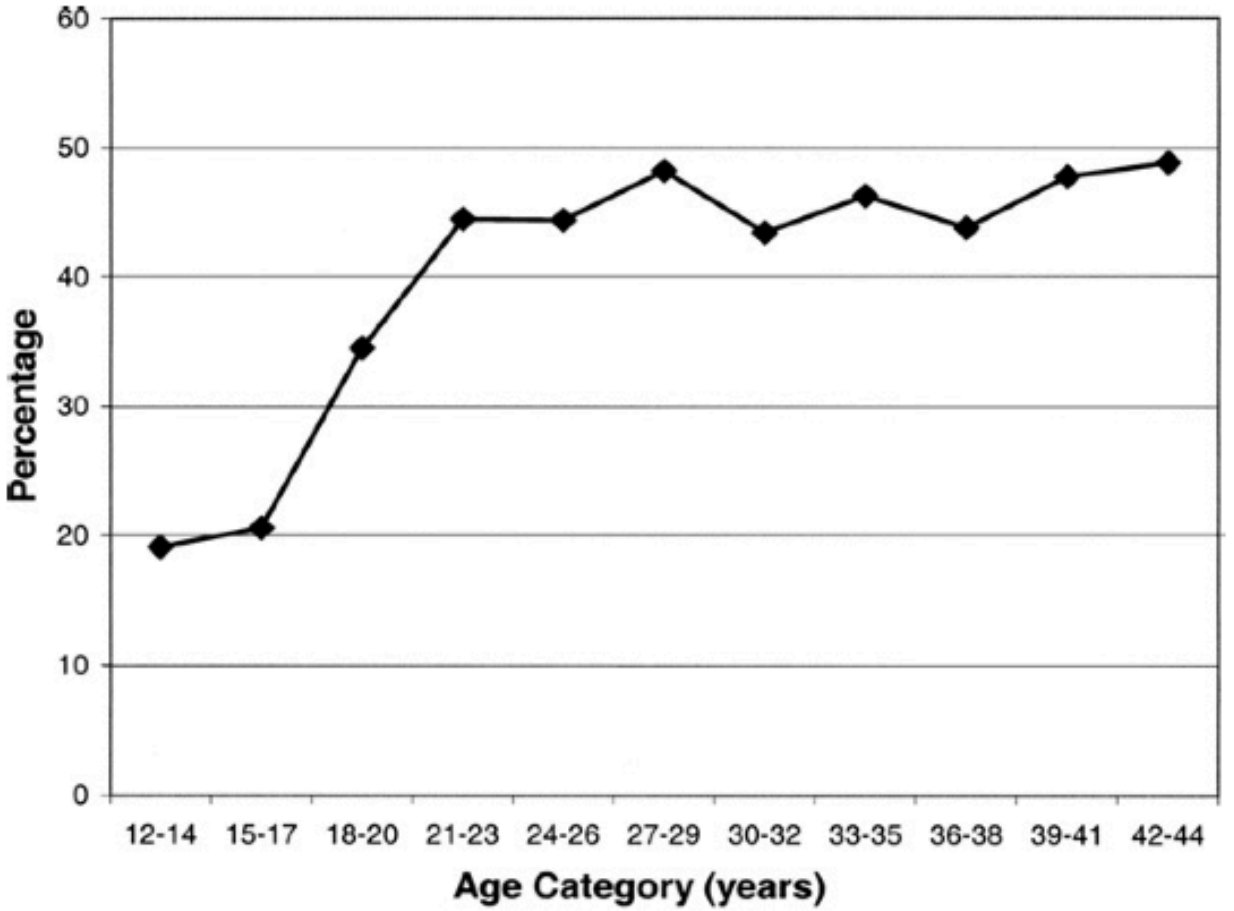
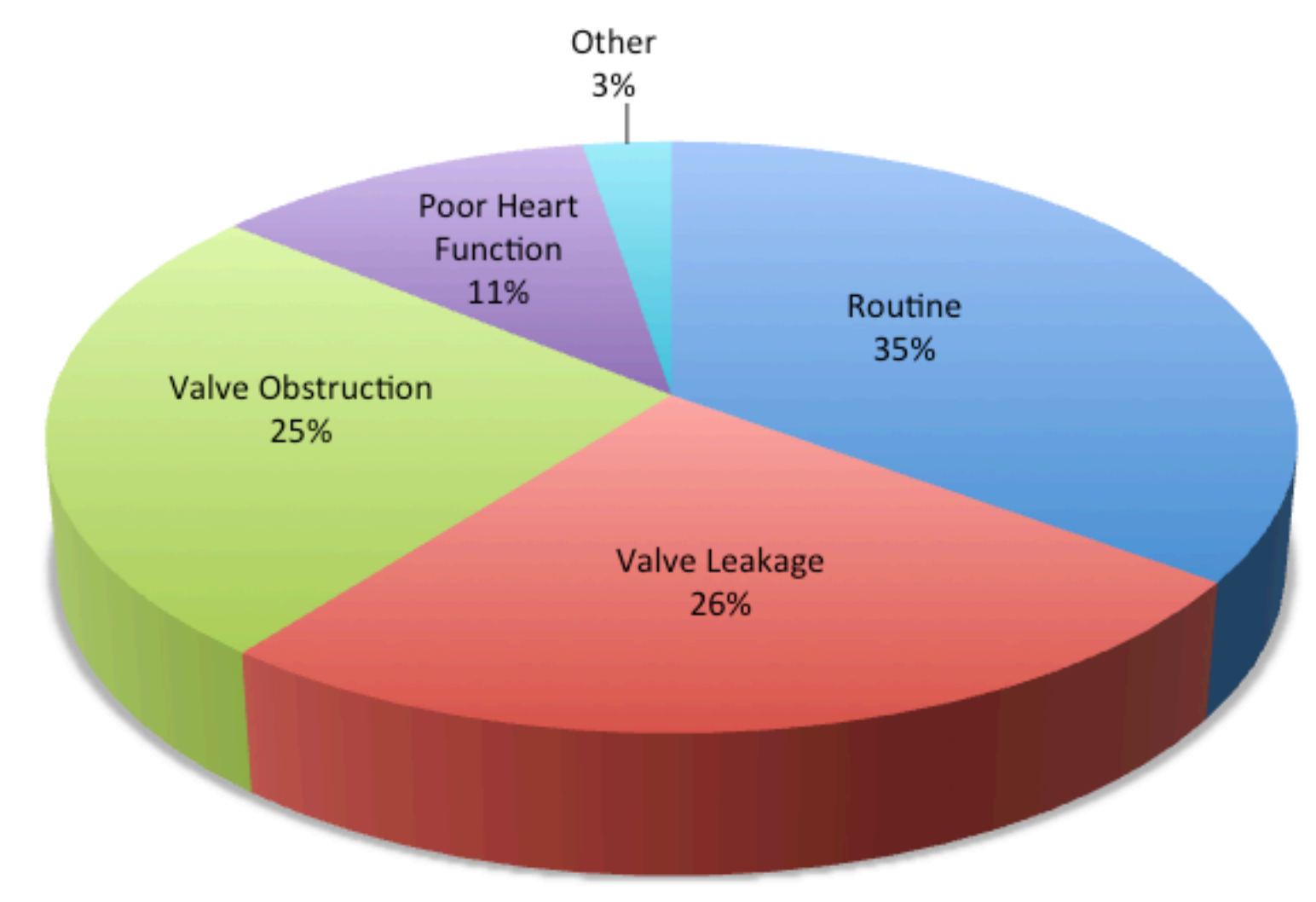


Figure 2 **Percentage of Admissions Via the ED for CHD Patients by Age Category, 2000 to 2003**

CHD = congenital heart disease; ED = emergency department.

(Gurvitz, JACC 2007)

Gaps in Care Associated with Increased Morbidity and Mortality



Yeung et al, Int. J. Cardiol. 2008;125(1):62-5)

Adolescent/Young Adult

- Lost to care
- Increase in ER use
- Increase in hospital admissions
- Poor compliance
- Increasing health costs

Adolescence

- Beginning of sexual maturity- independent adult
- Body image
- Dependence – independence struggle
- Sexuality
- High risk behaviors
- Peer relations

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Adolescence

- Body image
  - Scars
  - Small stature
  - Delayed puberty
- Dependence – independence struggle
- Sexuality
  - Decrease romantic relationships and sexual activity
  - STDs
  - Birth control
  - Pregnancy
- High risk behaviors
  - Similar engagement to the general populations
- Peer relations
  - School re-entry after extended absence
- Emotional disorders
  - Anxiety, depression

(Oswald 2012, Reid 2008, Klosky 2012, LaRosa 2011)

Transitioning

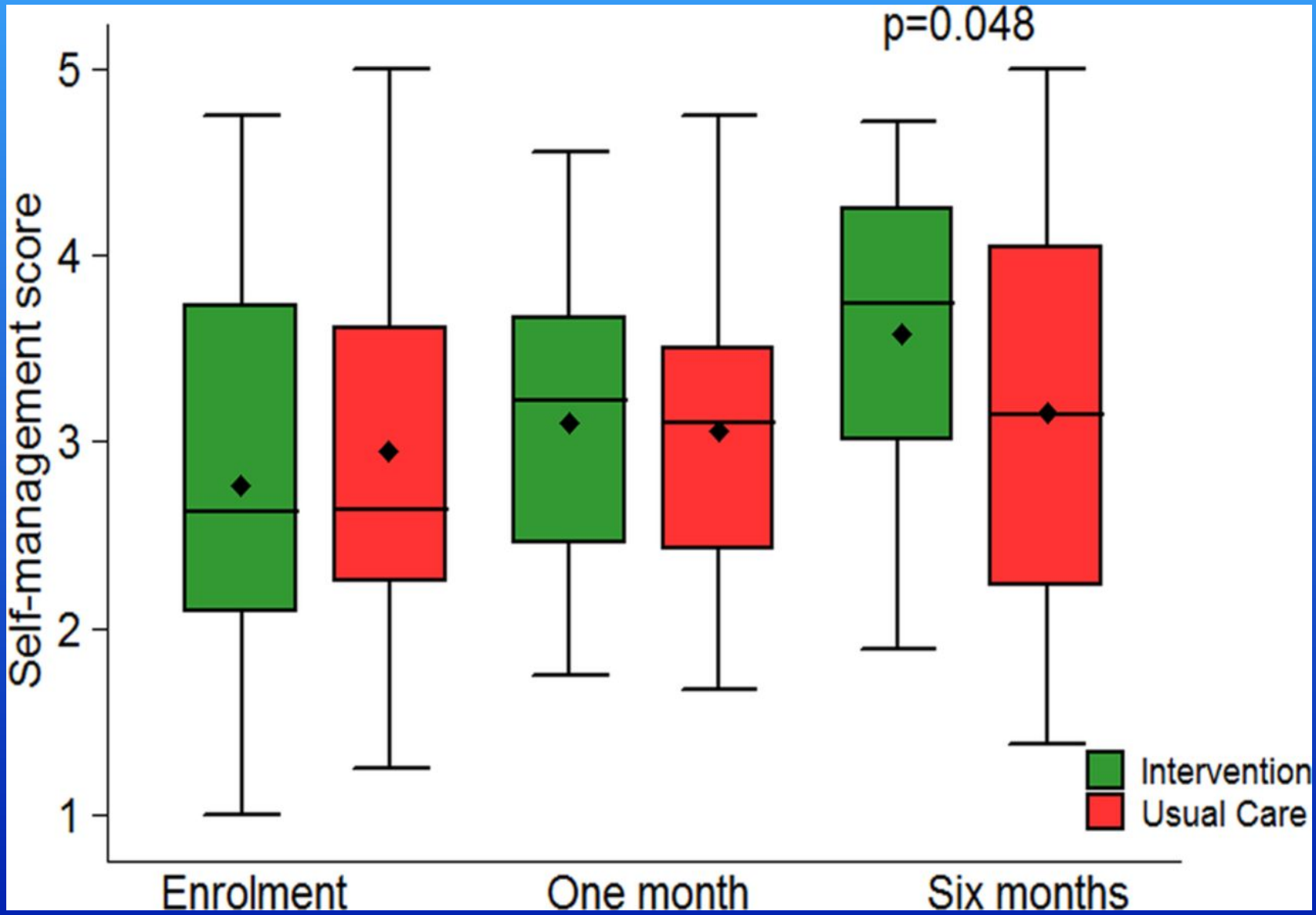
- Transitioning:
  - "The purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health-care systems" (Blum 1993)
- Transitioning:
  - "Process by which adolescents and young adults with chronic disease are prepared to take charge of their lives. It is an educational process that ideally begins before children reach adolescence and continues until they are capable of taking full responsibility of their care" (Knauth-Meadows 2008)
- Transitioning ≠ Transfer

Transitioning Education

- Randomized control trial:
  - ↓ Overall health care costs
  - ↓ Hospital re-admissions
  - ↓ Utilization of ER
  - ↑ Patient's functional recovery

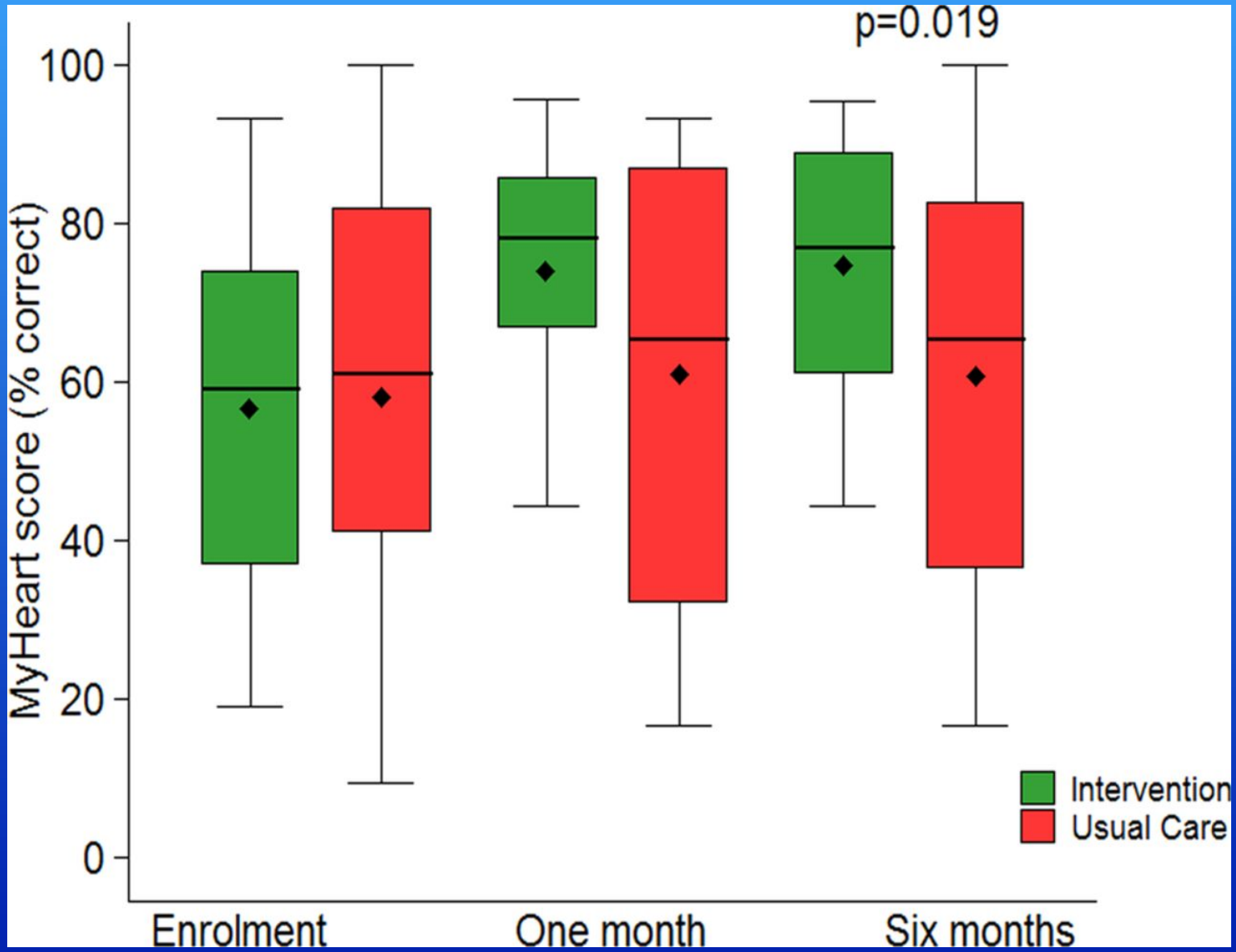
(*Coleman 2008)

Self-management Transition Readiness Assessment Questionnaire (TRAQ) scores



Mackie A S et al. Heart doi:10.1136/heartjnl-2014-305748

Congenital Heart Disease Knowledge



Mackie A S et al. Heart doi:10.1136/heartjnl-2014-305748

*Transitioning education for adolescents and young adults with pediatric onset chronic disease is now considered "**standard of care**" with the goal to "maximize lifelong functioning and potential." Despite this, transitioning education has not had "widespread implementation."*

(AAP, Pediatrics. 2011 July 1, 2011;128(1):182-200)

Report
Card
A+

Clinician Survey

- 563 Clinicians
  - Physicians
  - Nurses
  - Nurse practitioners
  - Physician assistants
  - Social workers

Int J Adolesc Med Health. 2010. 4(3):507-515.
Int J Child Adolesc Health. 2012. 5(3):145-148

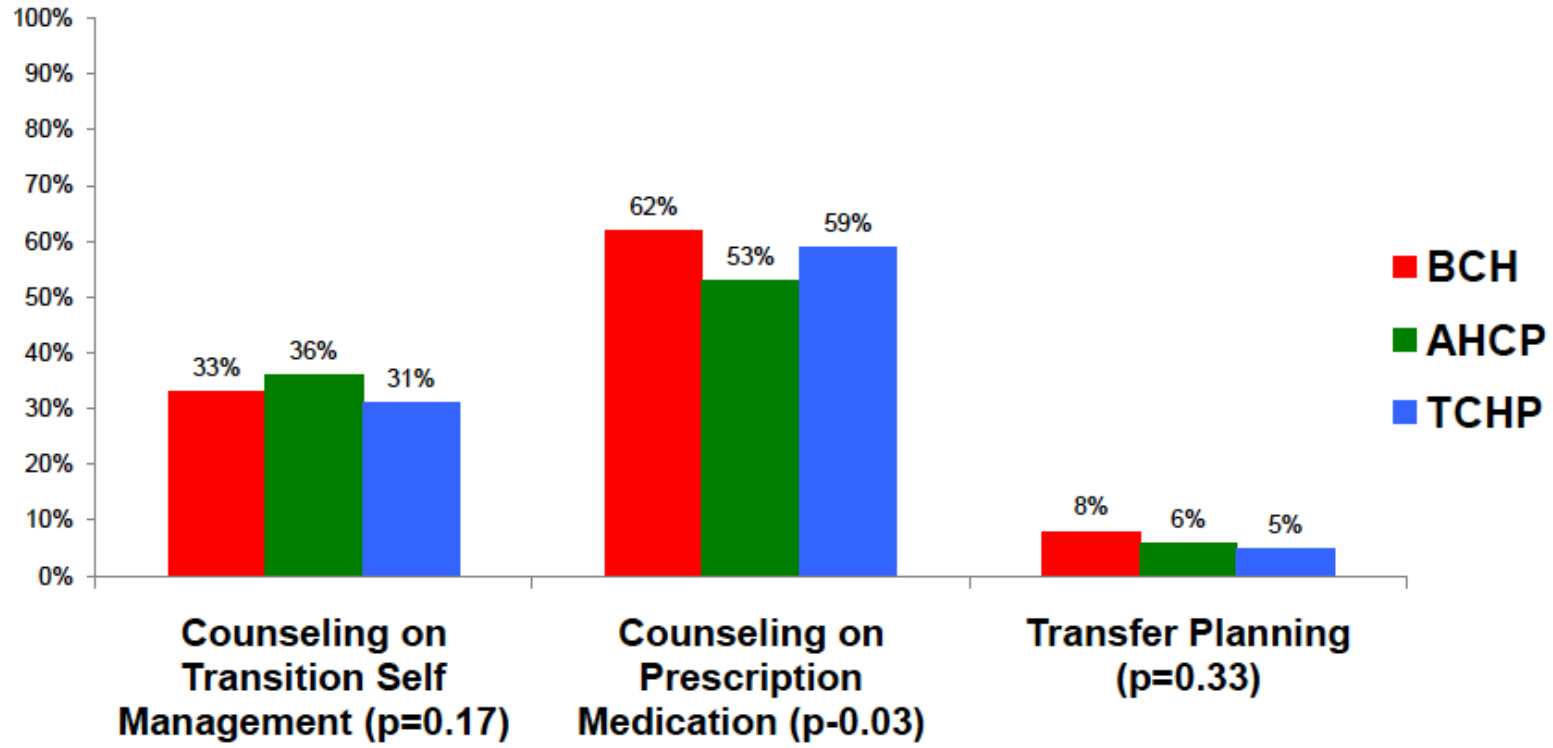
Transitioning Education

- Disease
  - Anatomy/surgery
  - Long term potential complications
- Medication use and side effects
- Symptoms that require urgent care
- Impact of disease on offspring
- Impact of high risk behaviors on disease
  - Alcohol
  - Tobacco
  - Illicit drug use
  - Unprotected intercourse
- Impact of disease on education, vocation and insurability

Transitioning Education

- 71% of clinicians stated their patients receive transitioning education
- 92% provide transitioning education informally
- 61% begin transitioning education before age 16 years

ADAPT Composite Scores by Site



*p-value using Fisher's exact test comparing scores across 3 sites

Patient/Parent Survey

- 166 Patients (16-25 years of age)
- 104 Parents

J Pediatr Rehabil Med. 2014 Jan 1;7(1):43-51

Table 1. Patient Characteristics

Total Responses	N=166
Age	
Mean±SD	18.8±2.3
Gender	
Female	92 (55.4%)
Diagnosis	
Cancer	27 (16.3%)
Type 1 diabetes	25 (15.1%)
Congenital heart disease	21 (12.7%)
Juvenile rheumatoid arthritis	19 (11.4%)
Hematologic disorder	19 (10.2%)
Inflammatory bowel disease	18 (10.8%)
Cystic fibrosis	11 (6.6%)
Solid organ transplant	8 (4.8%)
Genetic disorders	5 (3.0%)
Renal disease requiring dialysis	4 (2.4%)
Other	10 (6.0%)

J Pediatr Rehabil Med. 2014 Jan 1;7(1):43-51

Delivery of Transitioning Education: A Comparison of Patient and Parent Perceptions

Educational Topic	Patient	Parent	P value
Disease	92%	94%	NS
Medications	90%	100%	0.001
Medication side effects	79%	69%	NS
Symptoms requiring urgent intervention	77%	79%	NS

J Pediatr Rehabil Med. 2014 Jan 1;7(1):43-51

Delivery of Transitioning Education: A Comparison of Patient and Parent Perceptions

Educational Topic	Patient	Parent	P value
Unprotected intercourse	43%	18%	<0.001
Impact of disease on future offspring	32%	39%	NS
Birth control considerations and risk	45%	23%	0.009
Risk of pregnancy	33%	31%	NS

J Pediatr Rehabil Med. 2014 Jan 1;7(1):43-51

Delivery of Transitioning Education: A Comparison of Patient and Parent Perceptions

Educational Topic	Patient	Parent	P value
Risk of alcohol use	61%	38%	<0.001
Risk of tobacco use	52%	51%	NS
Risk of illicit drug use	48%	34%	0.019

J Pediatr Rehabil Med. 2014 Jan 1;7(1):43-51

Delivery of Transitioning Education: A Comparison of Patient and Parent Perceptions

Educational Topic	Patient	Parent	P value
Impact of disease on future education	60%	60%	NS
Impact of disease on future career/ vocation	28%	31%	NS

J Pediatr Rehabil Med. 2014 Jan 1;7(1):43-51

Transitioning Education

- Begin early
- Formalize processes
- Incorporate validated tools

Table 8-20 Sample Checklist for Transitioning of Care

NAME _____

MR# _____ DATE TRANSITION INITIATION ____/ ____/ _____

DATE OF BIRTH ____/ ____/ _____ DATE OF SKILL REVIEW ____/ ____/ _____

STATUS			
Completed	Practice	Initiate	Skill
			Patient can ask questions independently
			Patient can answer questions independently
			Patient is able to make follow-up appointments without support
			Patient is able to call for prescription refills or send mail order independently
			Patient can describe medical condition using appropriate terminology
			Patient can describe the long-term potential complications associated with his or her condition.
			Patient can describe symptoms that require immediate and semiurgent attention
			Patient can name his or her medications
			Patient understands the purpose of his or her medications and the side effects
			Patient understands the impact of medication mismanagement
			Patient has a healthcare passport
			Patient has a primary care physician (planned adult internist)
			Patient has a life/career plan for after high school/college
			Patient has a plan to pay for medical coverage after discontinuation of parent's health plan
			Patient understands impact of smoking
			Patient understands the impact of alcohol use
			Patient understands the risks of illicit drug use
			Patient understands the risk of pregnancy, sexually transmitted diseases, and contraception
			Patient understands the risk of congenital heart disease/anomalies in offspring (availability of genetic counseling for further information)
			Patient knows how to contact the hospital and outside support resources

With permission from the Boston Adult Congenital Heart Program.

TRAQ TOOL

Patient Name: _____ **Date** _____ **Person Completing Survey:** _____

Transition Readiness Assessment Questionnaire 3.0

Direction: We would like to know how you describe your skills in the areas that are important in your care. Your answers will help us provide services and education that will be important in preparing you to transition to adult health care. There are no right or wrong answers and your answers will remain confidential and private. Please check the box ☑ that you feel best describes you.

	I do not need to do this	I do not know how but I want to learn	I am leaning to do this	I have started doing this	I always do this when I need to
TRAQ DOMAIN 1: Skills for Chronic Condition Self-Management					
1. Do you fill a prescription if you need to?					
2. Do you know the side effects or bad reactions of each medication & what to do if you are having a bad reaction?					
3. Do you pay or arrange payments for your medications?					
4. Do you take medications correctly and on your own?					
5. Do you reorder medications before they run out?					
6. Do you use and take care of medical equipment and supplies?					
7. Do you call the suppliers when there is a problem with the equipment?					
8. Do you order medical equipment before they run-out?					
9. Do you arrange payment for the medical equipment and supplies?					
10. Do you call the doctor's office to make an appointment?					
11. Do you follow-up on any referral for tests or check-ups or labs?					
12. Do you arrange for your ride to medical appointments?					
13. Do you call the doctor about unusual changes in your health (Ex. Allergic reactions)?					
14. Do you apply for health insurance if you lose your current coverage?					
15. Do you know what your health insurance covers?					
16. Do you manage your money & budget household expenses (Ex. use checking/debit card)?					

Health Transition Assessment Tool (29 item) rev 12_08

	I do not need to do this	I do not know how but I want to learn	I am leaning to do this	I have started doing this	I always do this when I need to
TRAQ DOMAIN 2: Skills for Self-Advocacy and Health Care Utilization					
17. Do you fill out the medical history form, including a list of your allergies?					
18. Do you keep a calendar or list of medical and other appointments?					
19. Do you tell the doctor or nurse what you are feeling?					
20. Do you answer questions that are asked by the doctor, nurse or clinic staff?					
21. Do you ask questions of the doctor, nurse or clinic staff (Ex. What medications or treatments are best for you)?					
22. Do you make a list of questions before the doctor's visit?					
23. Do you request and get the accommodations & support you need at school or work?					
24. Do you apply for a job or work or vocational services?					
25. Do you get financial help with school or work?					
26. Do you help plan or prepare meals/food?					
27. Do you keep home/room clean or clean-up after meals?					
28. Do you use neighborhood stores and services (Ex. Grocery stores and pharmacy stores)?					
29. Do you call on and use community support services (Ex. After school programs) and advocacy services (Ex. Legal services) when you need them?					

Health Transition Assessment Tool (29 item) rev 12_08

J Pediatr Psychol. 2011 Mar;36(2):160-71

Patient Activation Measure (PAM) 13™

Insignia Health

Below are some statements that people sometimes make when they talk about their health. Please indicate how much you agree or disagree with each statement as it applies to you personally by circling your answer. Your answers should be what is true for you and not just what you think others want you to say.

If the statement does not apply to you, circle N/A.

1.	When all is said and done, I am the person who is responsible for taking care of my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
2.	Taking an active role in my own health care is the most important thing that affects my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
3.	I am confident I can help prevent or reduce problems associated with my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
4.	I know what each of my prescribed medications do	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
5.	I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
6.	I am confident that I can tell a doctor concerns I have even when he or she does not ask	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
7.	I am confident that I can follow through on medical treatments I may need to do at home	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
8.	I understand my health problems and what causes them	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
9.	I know what treatments are available for my health problems	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
10.	I have been able to maintain (keep up with) lifestyle changes, like eating right or exercising	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
11.	I know how to prevent problems with my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
12.	I am confident I can figure out solutions when new problems arise with my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
13.	I am confident that I can maintain lifestyle changes, like eating right and exercising, even during times of stress	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A

Insignia Health. "Patient Activation Measure; Copyright © 2003-2010, University of Oregon. All Rights reserved."
Contact Insignia Health at www.insigniahealth.com

Health Services Research. 2005: 40(6):1918-1930., Health Services Research. 2004:39 (4):1005-1026

TRANSITION-Q

McMaster Children's Hospital

TRANSITION-Q

McMaster University Health Sciences

PLEASE ANSWER THESE QUESTIONS ON YOUR OWN

Self-Management Skills scale: These questions are about being in charge of your health.
For each question, please circle only 1 answer.

	Never	Sometimes	Always
1. I answer a doctor's or nurse's questions.	0	1	2
2. I help to make decisions about my health.	0	1	2
3. I am in charge of taking any medicine that I need.	0	1	2
4. I talk to a doctor or nurse when I have health concerns.	0	1	2
5. I look for an answer when I have a question about my health.	0	1	2
6. I talk about my health condition to people when I need to.	0	1	2
7. I ask the doctor or nurse questions.	0	1	2
8. I speak to the doctor instead of my parent(s) speaking for me.	0	1	2
9. I summarize my medical history when I am asked to.	0	1	2
10. I contact a doctor when I need to.	0	1	2
11. I see the doctor or nurse on my own during an appointment.	0	1	2
12. I drop off or pick up my prescriptions when I need medicine.	0	1	2
13. I travel on my own to a doctor's appointment.	0	1	2
14. I book my own doctor's appointments.	0	1	2

DO NOT COPY

The Adolescent Assessment of Preparation for Transition (ADAPT) survey

YOUR EXPERIENCES GETTING HEALTH CARE

INSTRUCTIONS

Answer all the questions by checking the box next to your answer.

You are sometimes told to skip over some questions in this survey. When this happens you will see an arrow with a note that tells you what question to answer next, like this:

- ☑ Yes → **If Yes, go to #1**
- ☐ No

Your participation is voluntary. You may choose to answer the survey or not. If you choose not to, this will not affect the health care you get.

What to do when you're done. Please return the completed survey in the postage paid envelope.

1. Your main provider is the doctor or other health care provider who is in charge of the care for your health condition. If you have more than one health condition, please think about the condition that concerns you the most.
Is the provider named below your main provider?

Name of provider label goes here

- ☐ Yes
- ☐ No, my main provider is _____ *(please print)*

The questions in this survey will refer to the provider chosen in question 1 as "this provider." Please think of that provider as you answer the survey.

2. How long have you been going to this provider?
- ☐ Less than 6 months
- ☐ At least 6 months but less than 1 year
- ☐ At least 1 year but less than 3 years
- ☐ At least 3 years but less than 5 years
- ☐ 5 years or more

3. In the last 12 months, how many times did you visit this provider?
- ☐ None → **If None, go to #19**
- ☐ 1 time
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5 to 9
- ☐ 10 or more times

4. In the last 12 months, did you talk with this provider without your parent or guardian in the room?
- ☐ Yes
- ☐ No

5. In the last 12 months, did you and this provider talk about you being more in charge of your health?
- ☐ Yes
- ☐ No

6. In the last 12 months, did you and this provider talk about you scheduling your own appointments with this provider instead of your parent or guardian?
- ☐ Yes
- ☐ No

7. In the last 12 months, how often did you schedule your own appointments with this provider?
- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

8. In the last 12 months, did you and this provider talk about how your health insurance might change as you get older?
- ☐ Yes
- ☐ No

Your Prescription Medicines

9. In the last 12 months, did you take any prescription medicine?
- ☐ Yes → **If Yes, go to #10**
- ☐ No → **If No, go to #14**

10. In the last 12 months, how often did you and this provider talk about all of your prescription medicines at each visit?
- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

11. In the last 12 months, were you prescribed any medicine to take every day for at least a month?
- ☐ Yes → **If Yes, go to #12**
- ☐ No → **If No, go to #14**

12. In the last 12 months, did you and this provider talk about remembering to take your medicines?
- ☐ Yes
- ☐ No

13. In the last 12 months, did you and this provider talk about you refilling your own prescriptions instead of your parent or guardian?
- ☐ Yes
- ☐ No

Your Provider

14. Does this provider treat mostly children and teens?
- ☐ Yes → **If Yes, go to #15**
- ☐ No → **If No, go to #19**
- ☐ Don't Know → **If Don't Know, go to #15**

15. In the last 12 months, did you and this provider talk about whether you may need to change to a new provider who treats mostly adults?
- ☐ Yes → **If Yes, go to #16**
- ☐ No → **If No, go to #19**

16. In the last 12 months, did this provider ask if you had any questions or concerns about changing to a new provider who treats mostly adults?
- ☐ Yes
- ☐ No

17. In the last 12 months, did you and this provider talk about a specific plan for changing to a new provider who treats mostly adults?
- ☐ Yes → **If Yes, go to #18**
- ☐ No → **If No, go to #19**

18. Did this provider give you this plan in writing?
- ☐ Yes
- ☐ No

Transfer: Pediatric to Adult Oriented Care

Transfer

- Clinicians:
  - Lack of confidence in adult providers
  - Age as an indicator of transfer
  - Request for resources to streamline transfer process
- Parents:
  - Fear of letting go
  - Fear of being excluded from medical decisions
- Patients:
  - Sense of accomplishment by overcoming physical and emotional hurdles
  - Positive relationship with pediatric providers
  - Age as an indicator of transfer

Pediatric Nursing. 2014 May;40(3):113-20

Barriers to Adult-Oriented Care

- Lack of adult sub-specialists
- Parental and patient attachment to pediatric institution
- Adult internists feel incapable of providing care to adults with pediatric onset chronic disease; lack of resources to provided care coordination

Pediatrics. 2010 Apr;125(4):e748-54
Int J Adolesc Med Health. 2010. 4(3):507-515.

Adults in Pediatric Hospitals

- Staffed for children
- Equipped for children
- Most expensive type of care (Okumura et al. 2006; Tan et al. 2009).
  - Lower nursing to patient ratios
  - Lower threshold for ICU admissions
  - Provision of ancillary services (social work, child-life specialists)

Financial Impact

- $1 billion in total annual hospital charges for patients with SCD (Okumura et al. 2006).
- $3 billion in total hospital charges in 2005 for patients with CHD (Opotowsky, Siddiqi, and Webb 2009).

Adults in Pediatric Hospitals: Financial Impact

Table 4. Mean Hospital Charges for Adults With Chronic Conditions by Hospital Type*

Hospital Type	Hospital Charges for CCHD, Mean, $		Hospital Charges for CF, Mean, $		Hospital Charges for SCD, Mean, $		Hospital Charges for SB, Mean, $	
	Unadjusted	Adjusted†	Unadjusted	Adjusted†	Unadjusted	Adjusted†	Unadjusted	Adjusted†
Pediatric	68 345‡	63 498‡	56 742‡	69 213‡	33 925‡	28 891‡	30 214‡	30 900§
Mixed	34 160	34 312	35 108	31 831	18 473	17 963	23 561	24 876
Adult	29 687	28 904	32 766	30 668	17 677	16 697	23 994	22 467

Abbreviations: CCHD, complex congenital heart disease; CF, cystic fibrosis; SB, spina bifida; SCD, sickle cell disease.
*All of the data are weighted.
†Adjusted data reflect estimates adjusted for sex, age, whether inpatient death occurred, procedures, income, health insurance, and comorbidities.
‡$P \leq .001$
§$P < .01$.

Okumura et al. JAMA 2006

Adults in Pediatric Hospitals: Impact on LOS

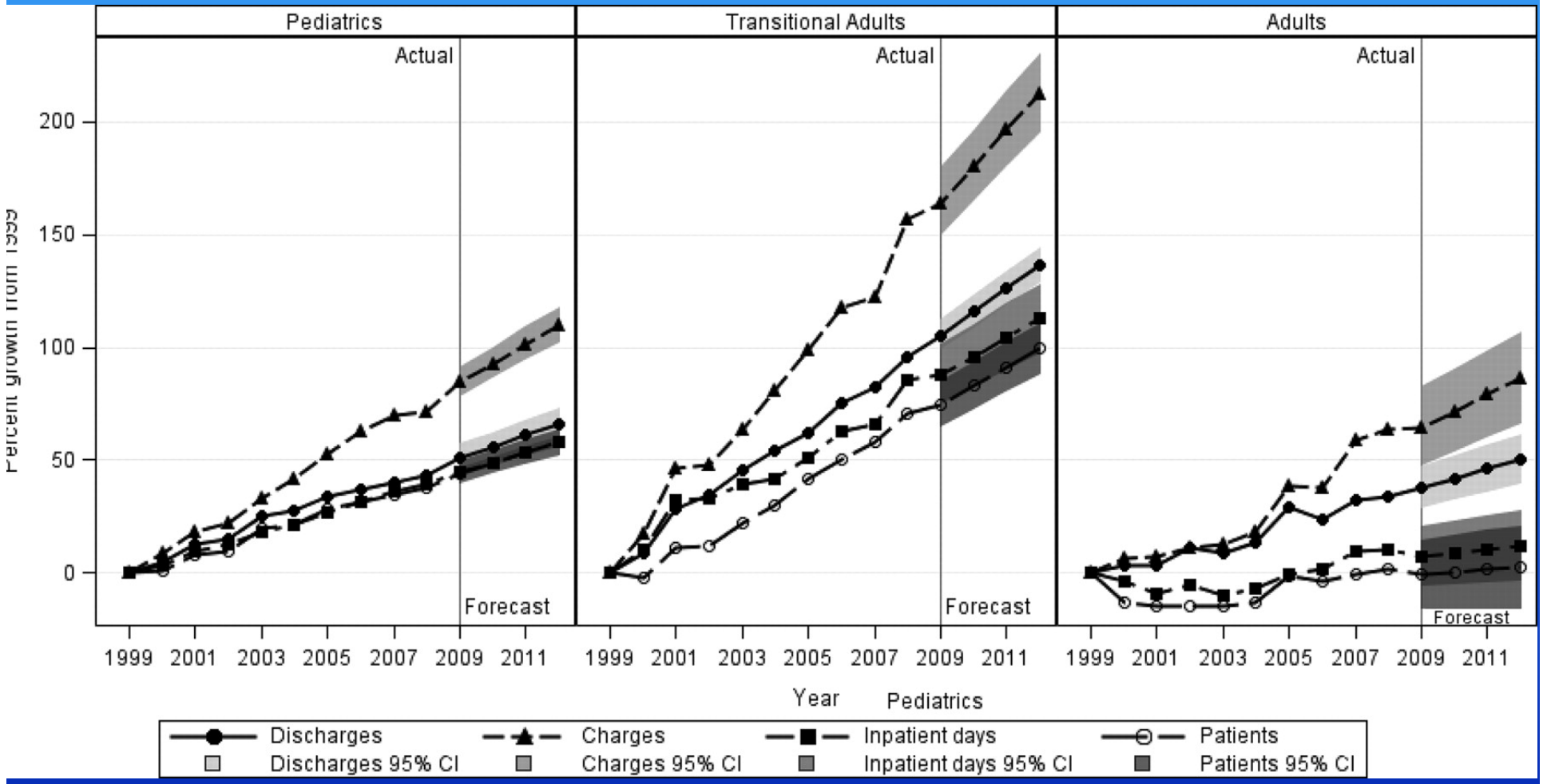
Table 3. Length of Stay for Adults With Chronic Conditions by Hospital Type*

Hospital Type	LOS for CCHD, d		LOS for CF, d		LOS for SCD, d		LOS for SB, d	
	Unadjusted	Adjusted†	Unadjusted	Adjusted†	Unadjusted	Adjusted†	Unadjusted	Adjusted†
Pediatric	7.7‡	7.7‡	10.9‡	12.0‡	6.8	6.8	6.1	6.7
Mixed	5.8	5.3	10.9	9.5‡	7.3	7.0	7.3	7.2
Adult	4.9	5.1	7.6	7.7	6.2	6.2	7.3	7.0

Abbreviations: CCHD, complex congenital heart disease; CF, cystic fibrosis; LOS, length of stay; SB, spina bifida; SCD, sickle cell disease.
*All of the data are weighted.
†Adjusted data reflect estimates adjusted for sex, age, whether inpatient death occurred, procedures, income, health insurance, and comorbidities.
‡$P \leq .001$.

Okumura et al. JAMA 2006

Increase in Adults Treated at Children's Hospitals, 1999–2012 according to age group



Goodman D M et al. Pediatrics 2011;128:5-13

Increase in Adults Treated at Children's Hospitals, 1999–2012 according to age group and disease

Cystic Fibrosis

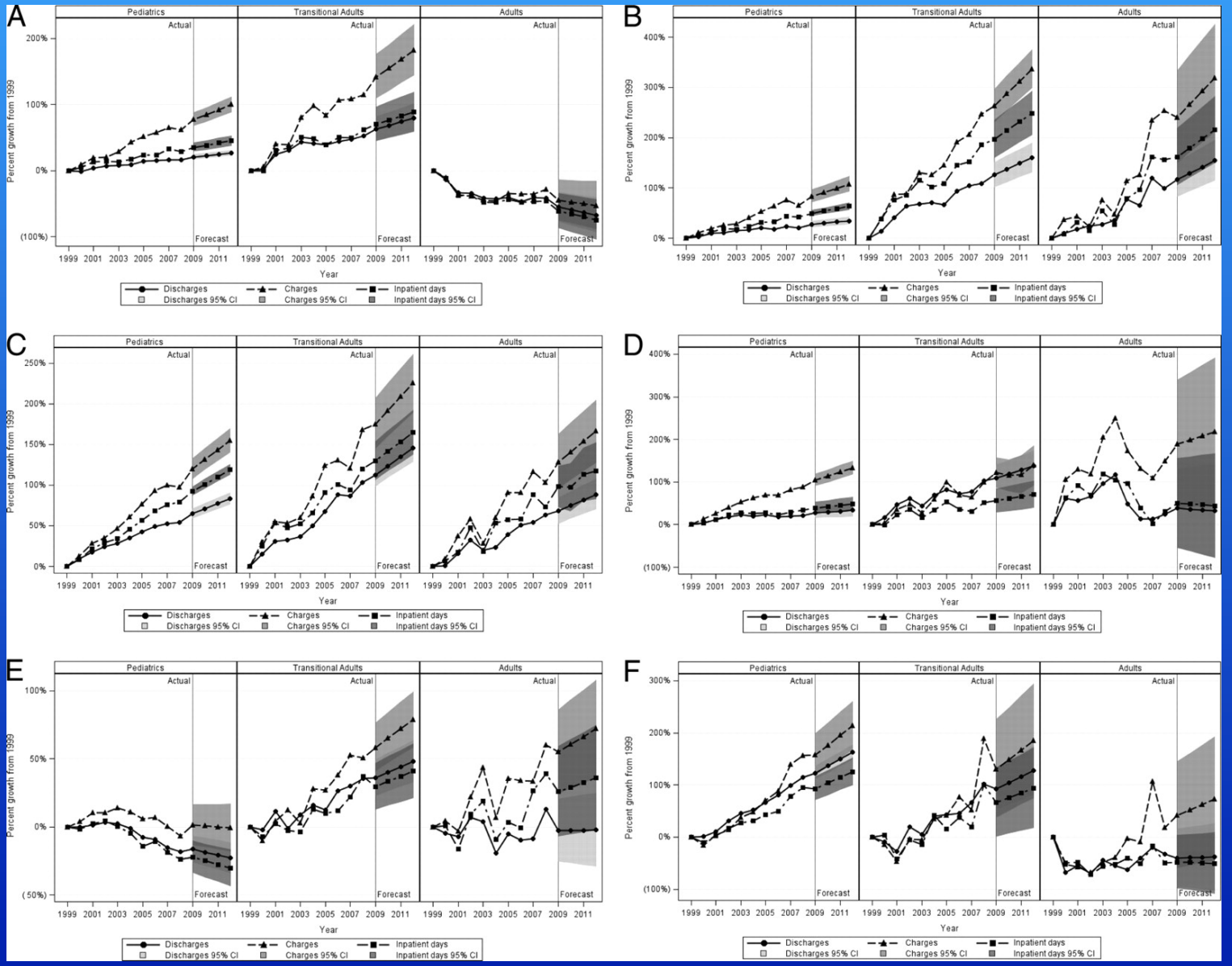
Cancer

CHD

Sickle Cell

Cerebral Palsy

Epilepsy

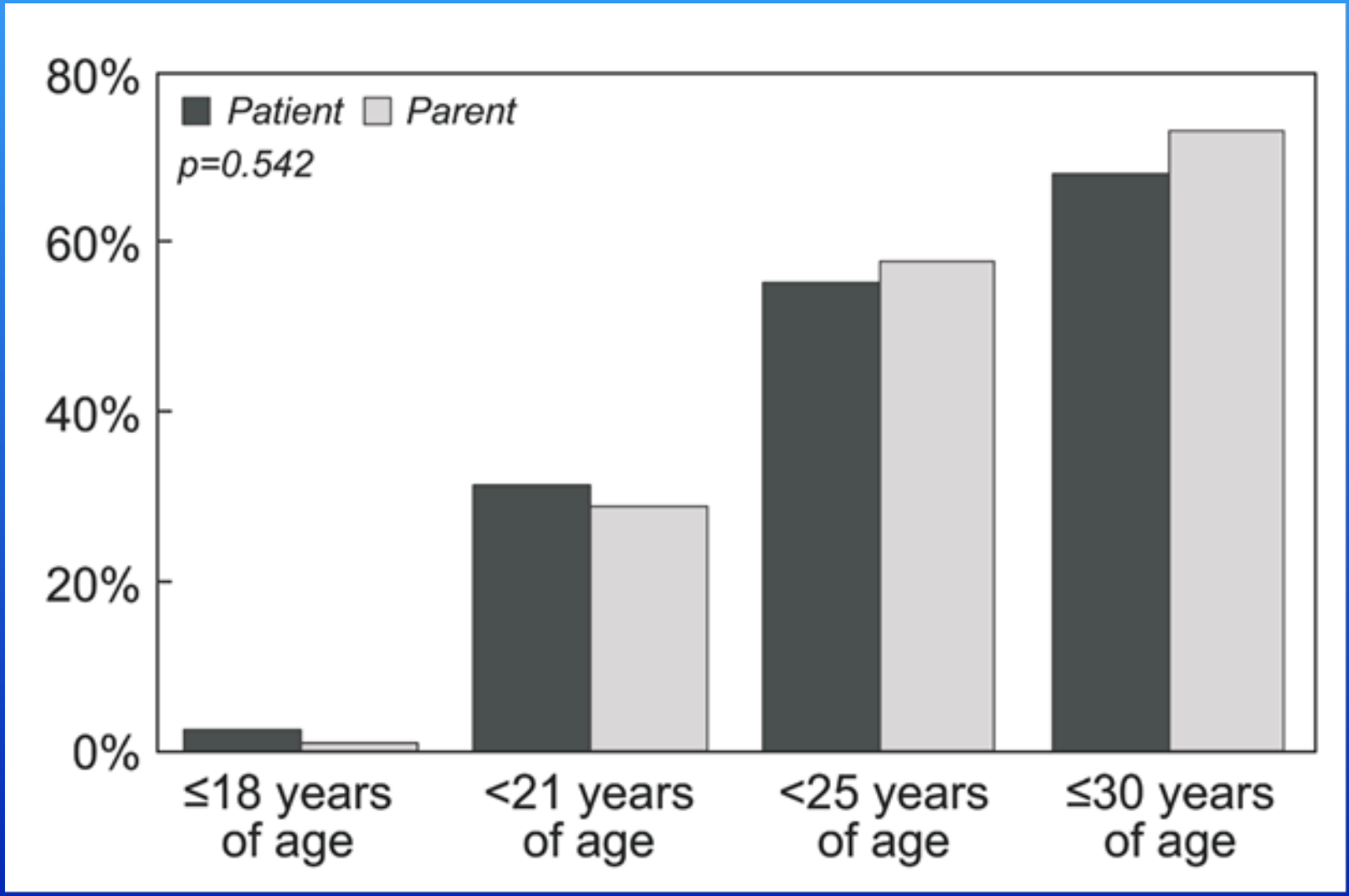


Goodman D M et al. Pediatrics 2011;128:5-13

Caring for Adults with Pediatric Disease

- Increasing number of hospitalizations
- Increasing health costs
- Increasing number of emergency room visits

Readiness for Transfer



J Pediatr Rehabil Med. 2014 Jan 1;7(1):43-51

Health Care Transitions

- ↑ Risk of morbidity
- ↑ Risk of death
- ↑ Healthcare resource utilization

Transfer

- Involve patient and family in plan
- Adult providers to pediatric environment
- Age
- Objective measures of readiness

Transfer

- Formalize hand-off
  - Pediatric and adult providers
  - Include patient and family

Celebration Time

Adult Congenital Heart Program

Stanford MEDICINE

a Lucile Packard Children's Hospital
and Stanford Health Care collaboration

visit us at achd.stanfordchildrens.org

AYA

Provision of Transition Education and Referral Patterns from Pediatric Cardiology to Adult Cardiac Care

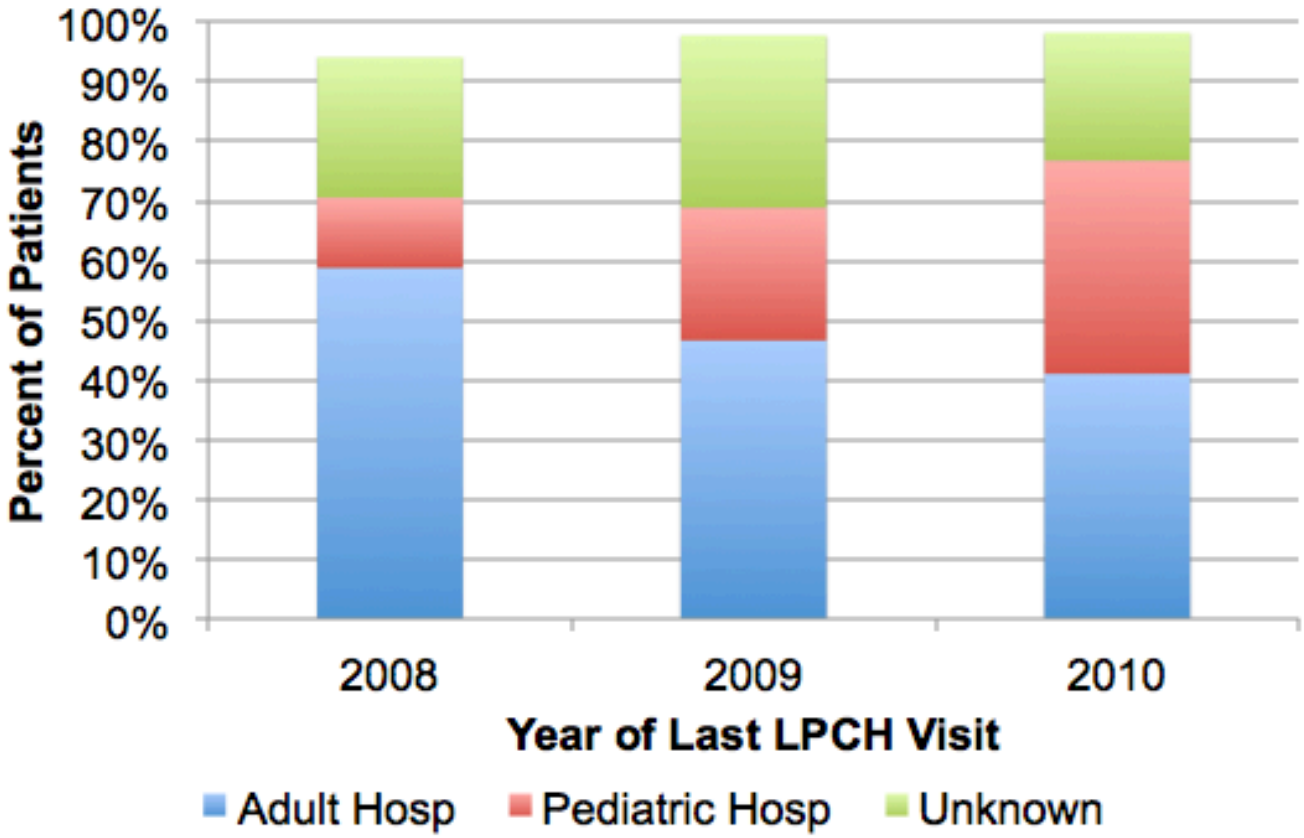
- 118 Patients
- ≥18 years of age between 2008-2011
- Seen in outpatient PC clinic

- CHD complexity
  - 14% simple
  - 42% moderate/complex
  - 42% other

Provision of Transition Education

Transition Education	Percent of Charts with Documented Transition Education
Disease	89%
Follow up	56%
Medications	55%
Exercise Limitations	34%
Dental Prophylaxis	24%
Symptoms requiring urgent intervention	10%
Medication side effects	7%
Dental Hygiene	5%
Risk of alcohol use	4%
Risk of illicit drug use	3%
Risk of pregnancy	2%
Dietary Concerns	2%
Birth control considerations	1%
Impact of disease on future career	1%
Unprotected intercourse	0%
Risk of Tobacco use	0%
Impact of disease on future offspring	0%
Impact of disease on future education	0%

Location of Follow up from Pediatric Cardiology Care



Of those told to transfer to adult-oriented care, 79% successfully transferred

Predictors of Successful Transfer

- Prior cardiac surgery (p=0.008)
- Cardiac medication use (p=0.006)
- Frequency of follow up ≤1 year (p=0.037)

LPCH Pediatric Cardiology

<18 yrs of age

AYA Heart
Transition Education
Adult Oriented Care

13-24 yrs of age

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>24 yrs of age

Transitioning/Adult-oriented Provider

Current instrument: **Demographics and Initial Intake**

Preview instrument

Variable: record_id

Record ID

NOTE: The field above is the record ID field and thus cannot be deleted or moved. It can only be edited.

Add Field | Add Matrix of Fields

Variable: patient_lookup

Patient Lookup

Add Field | Add Matrix of Fields

Variable: gender

Gender

Add Field | Add Matrix of Fields

Variable: ethnicity

Hispanic

Add Field | Add Matrix of Fields

Variable: race

Race

Add Field | Add Matrix of Fields

Variable: insurance1

Insurance

Add Field | Add Matrix of Fields

Variable: school

Highest level of education to date?

Add Field | Add Matrix of Fields

Variable: future_plans

Does the patient have a plan for the future (college, work etc)?

Add Field | Add Matrix of Fields

Variable: college_plans [Branching logic exists]

What type of college are they planning to attend?

Add Field | Add Matrix of Fields

Variable: type_work

What type of work is the patient planning to do?

Add Field | Add Matrix of Fields

Current instrument: **Transition (Self-Care Management) Education**

Preview instrument

Add Field | Add Matrix of Fields

Variable: visit_date

Date of visit [ ] Today M-D-Y

Add Field | Add Matrix of Fields

Variable: loc_visit

Location of Visit

- ○ 1. LPCH
- ○ 2. CPMC
- ○ 3. Emeryville
- ○ 4. Other

reset

Add Field | Add Matrix of Fields

Variable: transition_educ

Please choose all transitioning (self-care management) education that was provided on this visit?

- ☐ Diagnosis
- ☐ Prior Surgery
- ☐ Long term potential issues related to medical illness
- ☐ Indications for medications
- ☐ Medication side effects
- ☐ Implications of medication mismanagement
- ☐ Impact of tobacco use on underlying illness
- ☐ Impact of alcohol use on underlying illness
- ☐ Impact of illicit drug use on underlying illness
- ☐ Risks of unprotected intercourse
- ☐ Risks and benefits of contraception use
- ☐ Risks of pregnancy
- ☐ Impact of underlying illness on future offspring
- ☐ Impact of underlying illness on future education, career or vocation

Add Field | Add Matrix of Fields

Current instrument: **AYA Heart Clinic Exit Intake**

Preview instrument

Add Field | Add Matrix of Fields

Variable: diagnosis_explain

How well can the patient describe their medical condition?

Add Field | Add Matrix of Fields

Variable: passport

Does the patient have a health care passport?

Add Field | Add Matrix of Fields

Variable: pcp

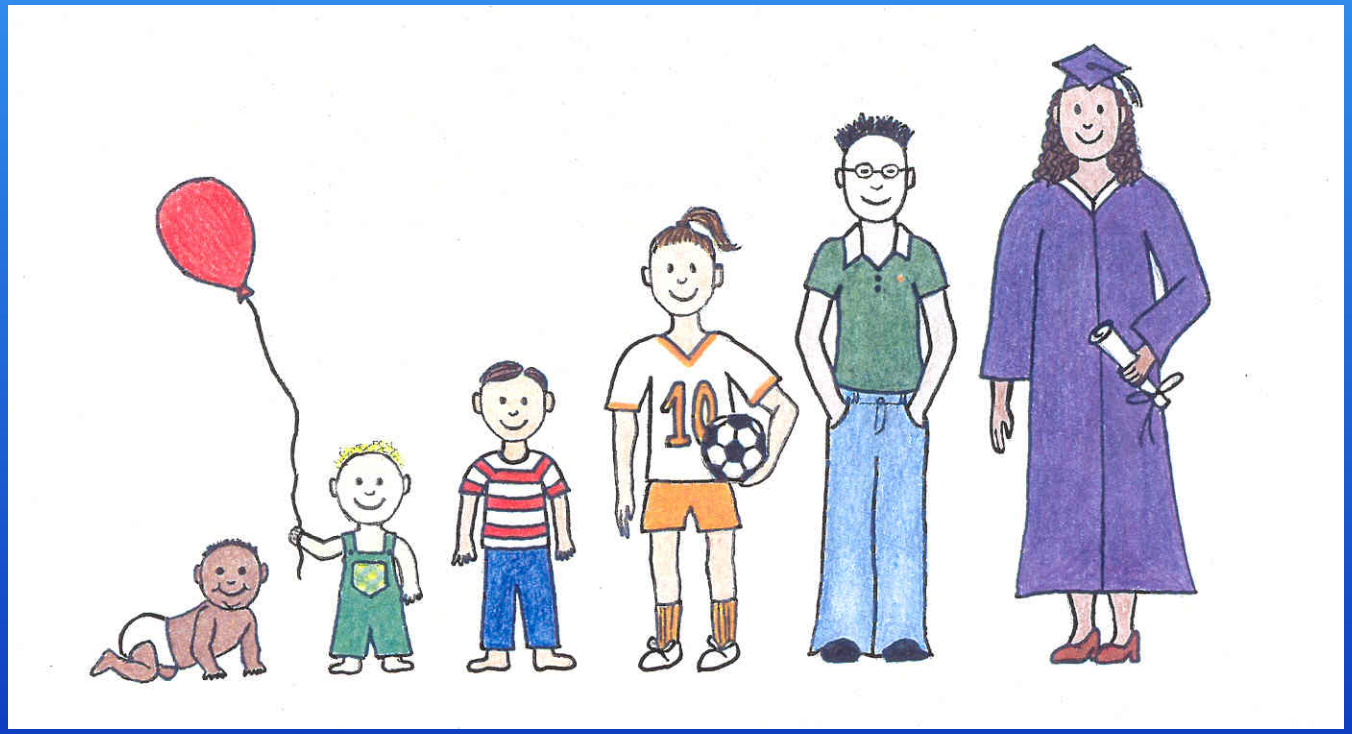
Does the patient have an adult internist or family practitioner?

Add Field | Add Matrix of Fields

Variable: insurance

Has the patient's insurance been reviewed to ensure there is no access to care issues?

Add Field | Add Matrix of Fields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