

Development of an Adolescent-Reported Measure Assessing the Quality of Health Care Transition Preparation

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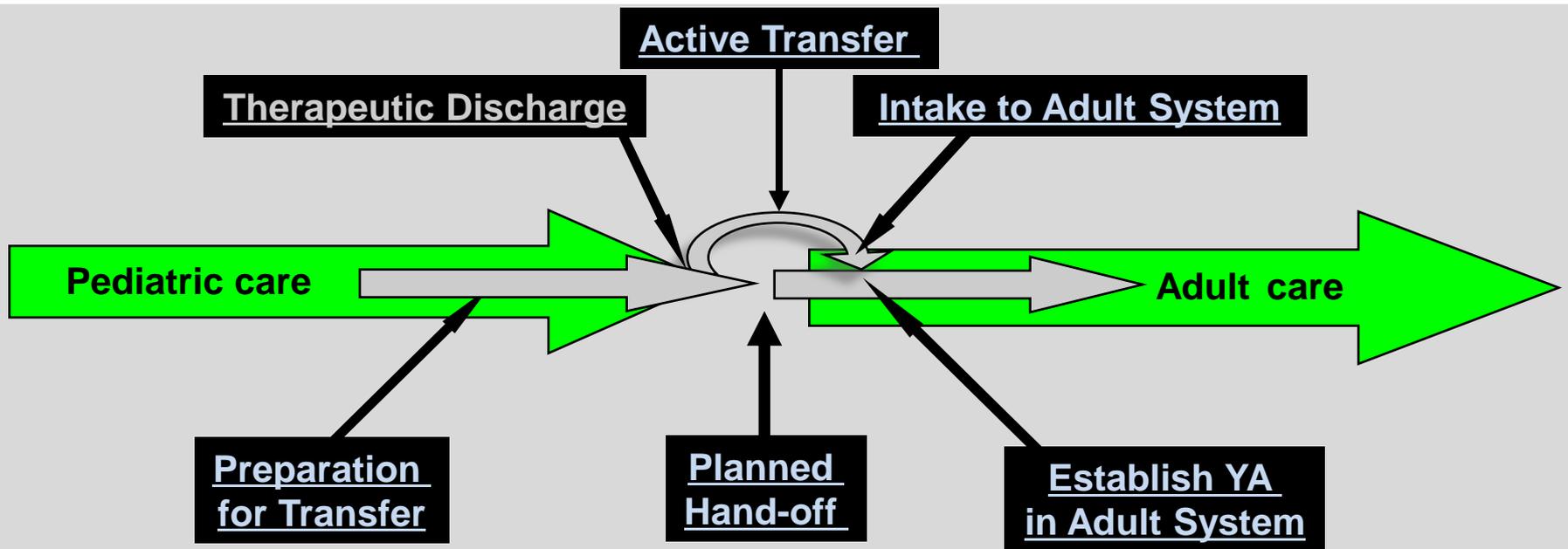
Boston Children's Hospital

Harvard Medical School



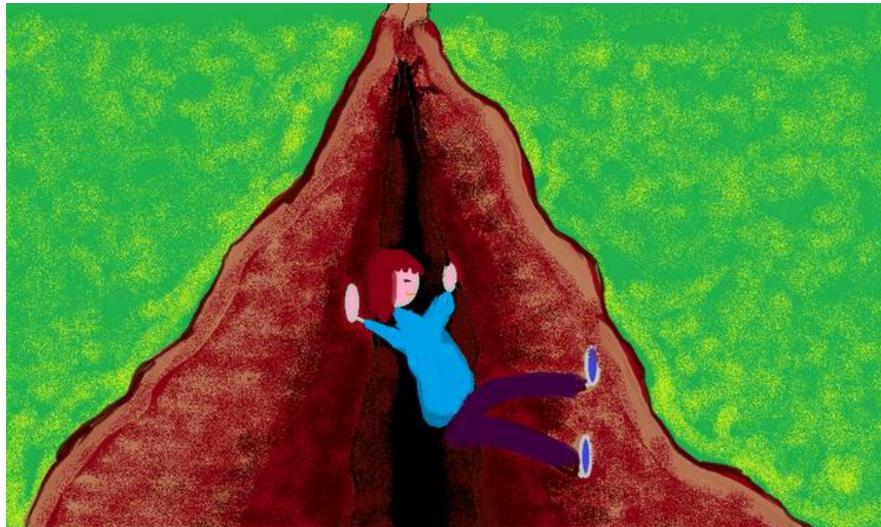
Health care transition (HCT) encompasses the process of preparing youth for the eventual move to adult-oriented care

- GOAL: provide high-quality and developmentally-appropriate health services in an *uninterrupted* manner

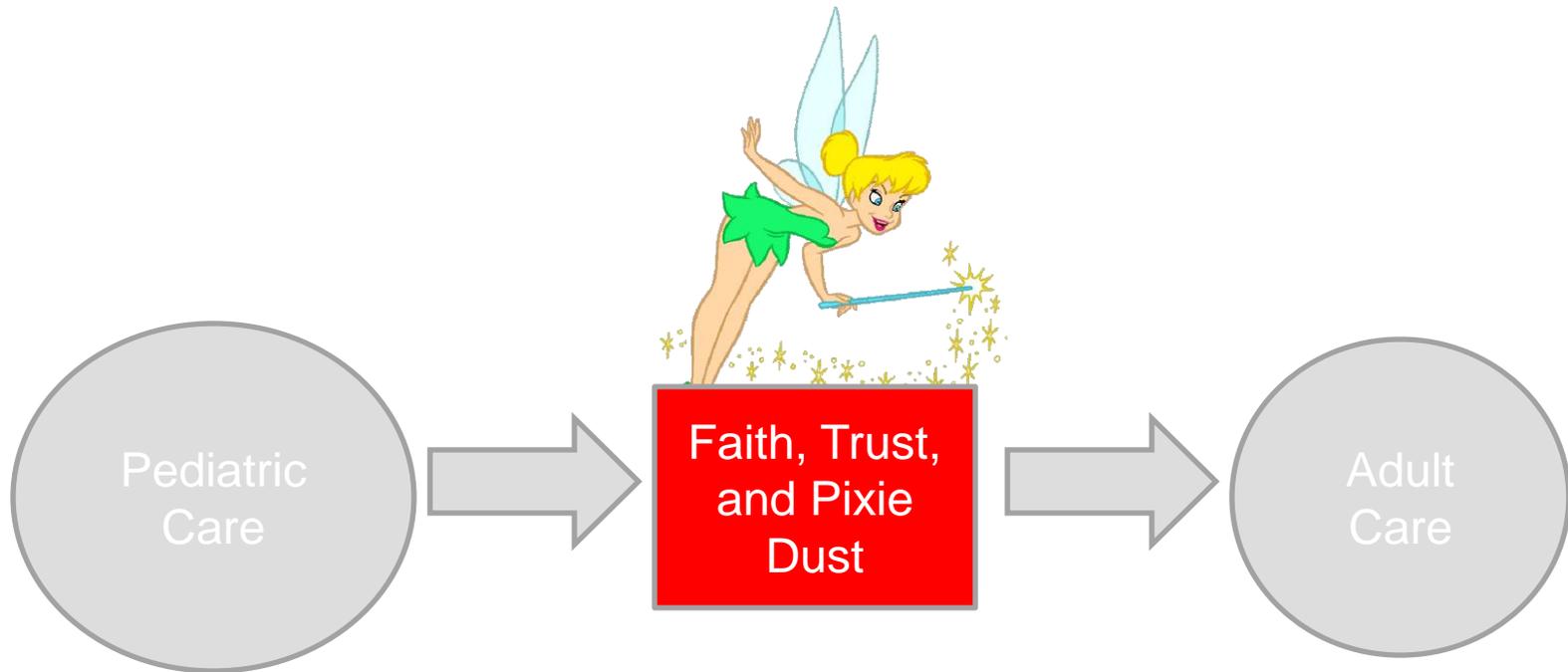


Health Care Transition (HCT)

- Lack of effective HCT may lead to:
 - Fragmentation of health care
 - Increased risk for adverse health outcomes



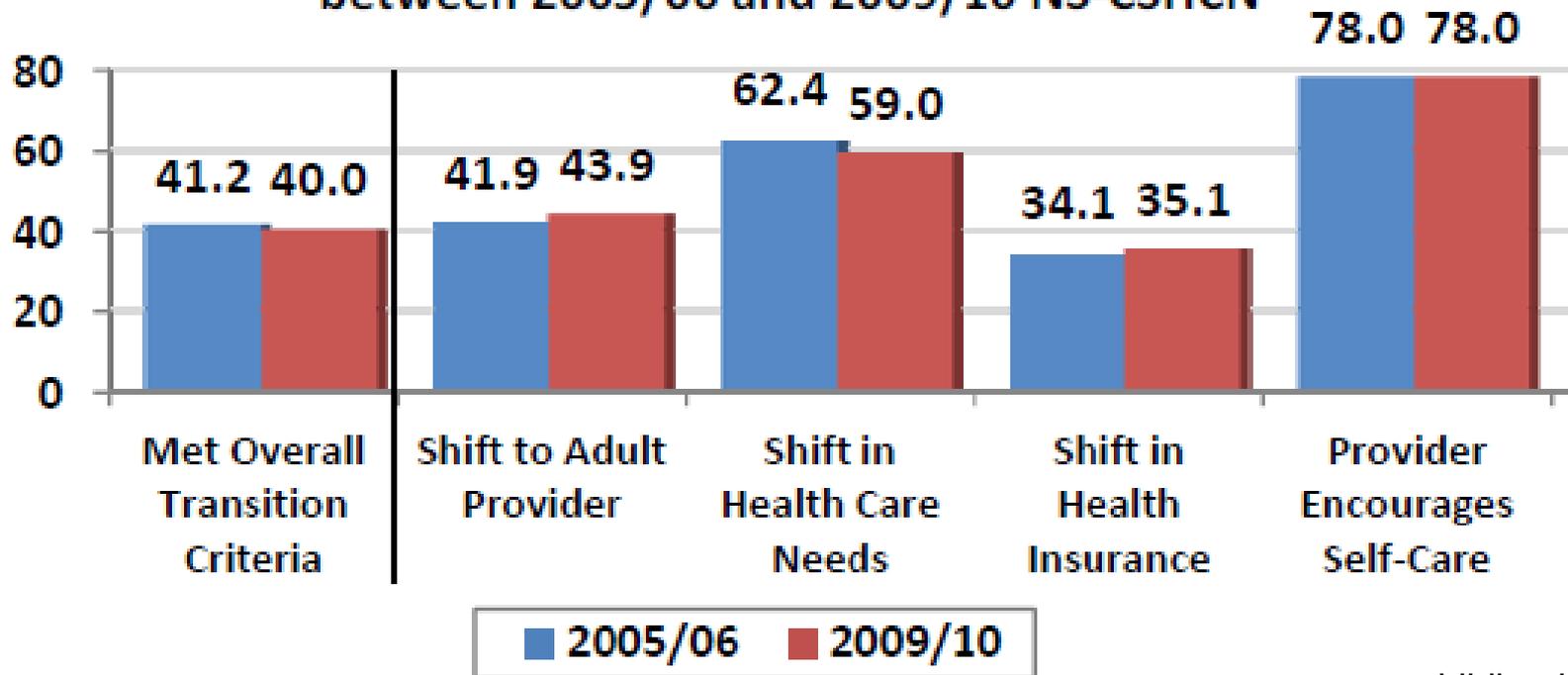
The Current State of U.S. Transitions?



Preparation for HCT: A Quality Gap

- National Survey of Children with Special Health Care Needs (NS-CSHCN) – *Parent report*

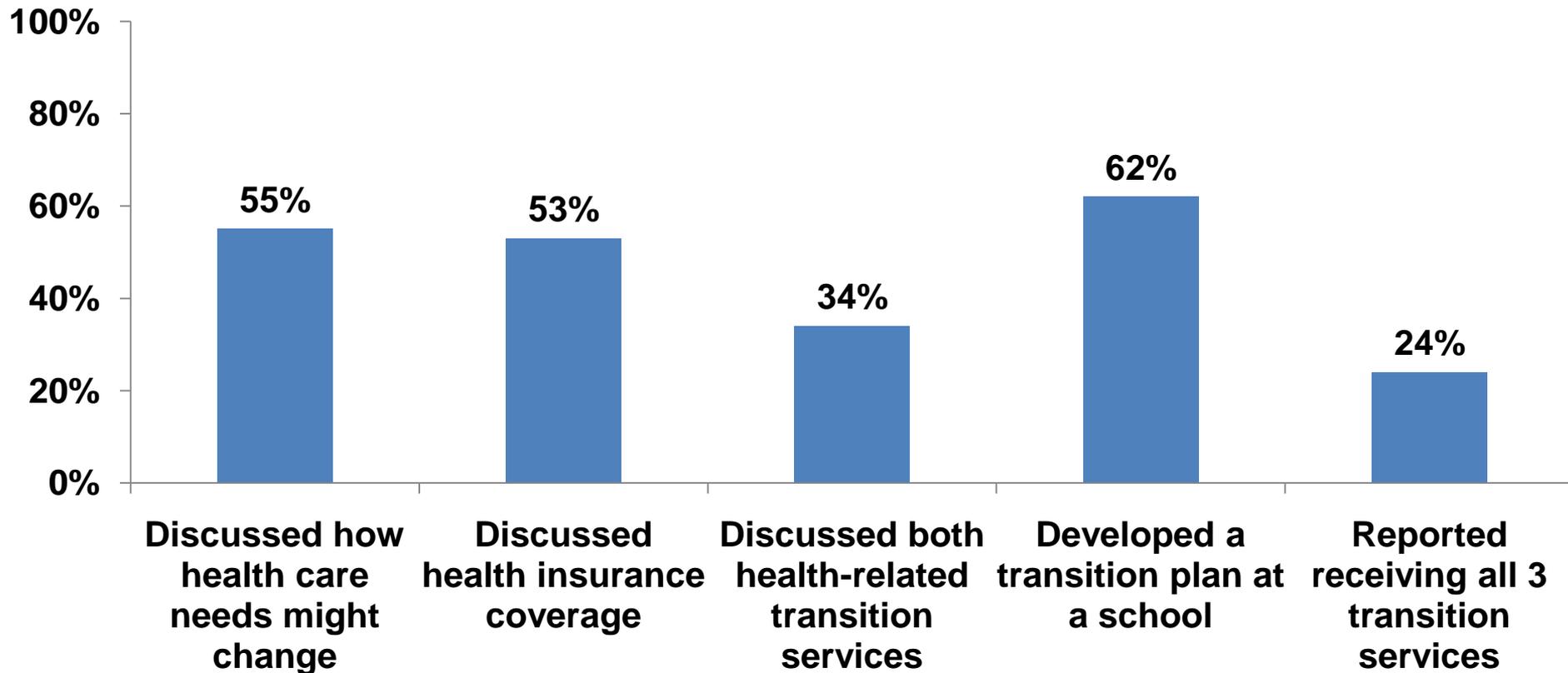
Shifts in Prevalence of Transition to Adulthood Discussions
between 2005/06 and 2009/10 NS-CSHCN



www.childhealthdata.org

Preparation for HCT: A Quality Gap

2007 Survey of Adult Transition and Health: *Young Adult Report*



Preparation for HCT: Adolescent Perspective

- No survey has **directly assessed adolescents' report** of the quality of transition preparation counseling



A New Measure

- The **ADAPT** (**AD**olescent **A**ssessment of **P**reparation for **T**ransition) survey is a youth-reported measure of the quality of health care transition preparation.

Overview of Measure Development

- Literature Review
- Expert interviews
- Focus groups
- Cognitive interviews
- National field test
- Psychometric analysis
- Composite development

Focus Groups

- 11 focus groups
 - Adolescents (16-18) and young adults (19-26) with chronic health conditions, as well as parents
 - Boston, Chicago, Los Angeles
 - Goal to inform domains and items for survey measure
- Major themes:
 - *16-18 year-olds: Ignorance and Fear*
 - *19-26 year-olds: Suboptimal Preparation*
 - *Parents: Concern about Changing Roles*
- The ADAPT survey was developed following the focus groups and refined via a series of cognitive interviews

The ADAPT Survey

- Mail survey designed for adolescents:
 - Age 16 or 17
 - With a chronic health condition(s)
 - Receiving health care services in a clinical program or enrolled in a health plan
- 26 questions total
- Three composite measures:
 - Counseling on Transition Self-Management (5 questions)
 - Counseling on Prescription Medication (3 questions)
 - Transfer Planning (4 questions)

Counseling on Transition Self-Management

This composite is produced by combining responses to five questions:

- **Q4: In the last 12 months, did you talk with this provider without your parent or guardian in the room?**
- **Q5: In the last 12 months, did you and this provider talk about your being more in charge of your health?**
- **Q6: In the last 12 months, did you and this provider talk about your scheduling your own appointments with this provider instead of your parent or guardian?**
- **Q7: In the last 12 months, how often did you schedule your own appointments with this provider?**
- **Q8: In the last 12 months, did you and this provider talk about how your health insurance might change as you get older?**

Counseling on Prescription Medication

Respondents who answer “Yes” to both Questions 9 and 11 are included in the population for which this composite is calculated.

- **Q9: In the last 12 months, did you take any prescription medicine?**
- **Q11: In the last 12 months, were you prescribed any medicine to take every day for at least a month?**

This composite is produced by combining responses to three questions:

- **Q10: In the last 12 months, how often did you and this provider talk about all of your prescription medicines at each visit?**
- **Q12: In the last 12 months, did you and this provider talk about remembering to take your medicines?**
- **Q13: In the last 12 months, did you and this provider talk about you refilling your own prescriptions instead of your parent or guardian?**

Transfer Planning

Respondents who answer “Yes” or “Don’t Know” to Question 14 are included in the population for which this composite is calculated.

- **Q14: Does this provider treat mostly children and teens?**

This composite is produced by combining responses to four questions:

- **Q15: 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?**
- **Q16: 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?**
- **Q13: 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?**
- **Q18: Did this provider give you this plan in writing?**

Fielding the Survey

- Eligibility criteria
 - 16-17 years old
 - At least one chronic health condition
 - Clinical program: at least one visit during in the preceding 12 months
 - Health plan: current enrollment over the preceding 12 months with at least one administrative claim
- Sampling strategy
 - Clinical program: use Simple Random Selection (SRS) to draw from eligible patients
 - Health plan: apply an algorithm to claims data to determine eligibility, then use SRS to draw final sample

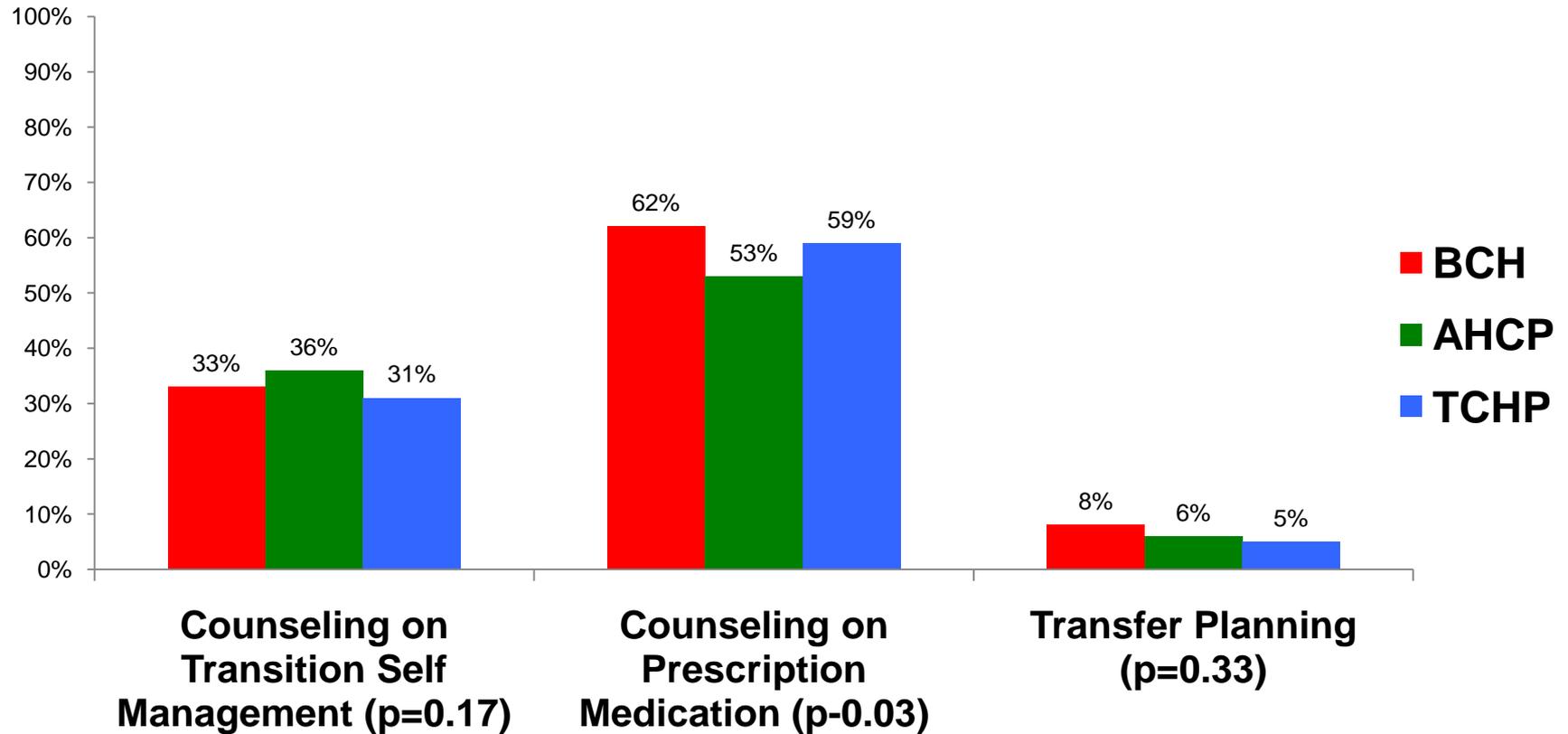
National Field Test

- **Dates:**
 - August 2013 – April 2014
- **Location:**
 - Massachusetts: Boston Children's Hospital
 - » 623 surveys mailed, 293 returned (47% response rate)
 - Pennsylvania: AmeriHealth Caritas Pennsylvania (AHCP)
 - » 3,000 surveys mailed, 780 returned (28% response rate)
 - Texas: Texas Children's Health Plan (TCHP)
 - » 3,000 surveys mailed, 559 returned (21% response rate)

Respondent Demographics

	BCH	AHCP	TCHP
Gender (% female)	54%	51%	56%
Age (% 16 years old)	42%	45%	40%
Insurance (% public)	29%	100%	100%
Education:			
9th grade or less	7%	15%	10%
10th grade	39%	37%	33%
11th grade	47%	39%	38%
12th grade or more	7%	9%	19%
Race:			
White	83%	51%	16%
Black	5%	26%	19%
Hispanic	7%	15%	58%
Other	5%	8%	8%

ADAPT Composite Scores by Site



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

Differences By Age or Gender?

- No differences in composite scores based on gender at any site
- 17 year olds had higher average scores in Transfer Planning in 2 sites
 - No differences in other composites

Reliability and Validity

- Internal consistency reliability (ordinal alpha)

	BCH	AHCP	TCHP
Counseling on Transition Self Management	.79	.70	.78
Counseling on Prescription Medication	.57	.78	.74
Transfer Planning	.99	.99	.99

- Confirmatory factor analysis supported the hypothesis that the individual items *within* each of the first two domains are associated with one another

Limitations of the ADAPT Survey

- Cannot evaluate all important facets of HCT preparation
- Parents/guardians may be able to provide better information than adolescents about some aspects of HCT preparation
- Mail surveys may lead to bias / uncertainty on who answered
- Not appropriate to assess HCT preparation for adolescents who have cognitive or developmental delay.

Summary

- The ADAPT survey is a reliable, validated, patient-reported instrument to measure the quality of HCT preparation in adolescents with chronic disease
- Results from the field tests indicate that preparation for HCT is suboptimal
 - Overall, the quality of HCT preparation is highest for prescription medication counseling
 - Low levels of counseling on self-management and transfer planning are evident among adolescents in varied settings

Future Directions

- Expanded use of the ADAPT survey will allow for comparisons based on other clinical and sociodemographic factors
- The ADAPT survey will enable health care delivery systems to assess the quality of provision of HCT preparation and provide targets for improvement in patient counseling related to transition

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Staff of the Center of Excellence for Pediatric Quality Measurement (CEPQM) at Boston Children's Hospital

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