Transition of care

From Playstation to Workstation

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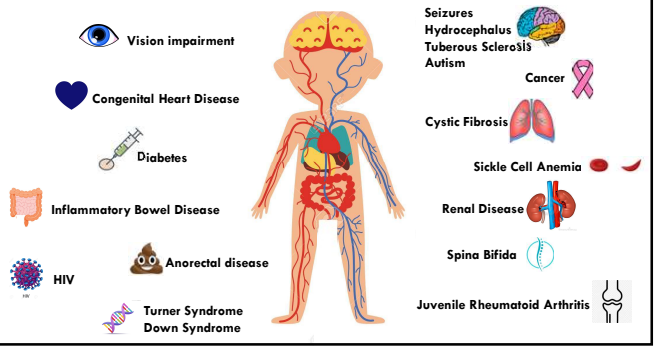
Disclosure statement

No financial interest or affiliation concerning material discussed in this presentation

Will not discuss any non-FDA approved or investigational drugs/medical devices

Publications focused on transition of care for specific pediatric diseases



~~Fountain~~ Tidal Wave of Youth

- Millennial generation (1982-2000) > Baby Boomers by 10%
- 19% of US population (61 million) aged 12-26 years old
  - 25-30% have one or more chronic conditions
    - >90% of these survive to adulthood
- 500,000 children with special healthcare needs turn 18 every year
- 2.4 million people living with Congenital Heart Disease in the US
  - 1.4 million adults
  - 1 million children

J Adolesc Health Vol 63 (2018)

A problem generated by our own success

Providers Aren't Prepared

- National survey of AAP Fellows revealed the need for more information and support regarding transitions
- 4.2% of MDs receive formal training during Residency
- Comfort level with transition among pediatricians is 2.6 out of 5
- Only 56% of adult rheumatologists felt comfortable caring for former pediatric patients

Military Medicine, Volume 183, Issue 11-12, November-December 2018, Pages e676–e679

Arthritis Care Res; 2019: Feb 11

Hospitals Aren't Prepared

TABLE 2 Chronic Conditions Among Patients Hospitalized at Children's Hospitals in 2007 and 2008

	Pediatrics (<18 y), *n* (%)	Transitional (18–21 y), *n* (%)	Adults (>21 y), *n* (%)
CF	7003 (1.0)	1426 (6.9)	1055 (14.4)
Malignant neoplasms	69 773 (10.1)	4283 (20.6)	1451 (19.8)
Sickle cell disease, median (interquartile range), %	18 706 (2.7)	1825 (8.8)	136 (1.9)
CHD	113 684 (16.4)	4275 (20.5)	2121 (28.9)
Cerebral palsy, median (interquartile range), %	15 924 (2.3)	1300 (6.2)	647 (8.8)
Epilepsy and recurrent seizures, median (interquartile range), %	10 815 (1.6)	239 (1.1)	59 (0.8)
Other chronic condition	95 440 (13.8)	3491 (16.8)	888 (12.1)
No identified chronic condition	360 614 (52.1)	3976 (19.1)	988 (13.5)

Values are the sum of 2007 and 2008 discharges.

Parents Aren't Prepared

- 26% of mothers and 36% of fathers haven't started thinking about transition (parents of 14-18 year-olds with CHD)
- Illness uncertainty may have an impact on the psychological functioning and distress in parents to children with pediatric chronic illnesses (anxiety, depression, and psychological distress)

Patients Aren't Prepared

- Developmental stage is marked by struggles for independence, identity exploration, psychosocial instability, and self-focus.
- Brain neural pathways are not yet completely matured, manifesting as a lag in executive function, including organizational skills and judgment, as well as in emotional regulation
  - Desire for independence often exceeds capabilities for responsibility, rendering interdependence a more viable option.
- young adults use outpatient services significantly less often than younger or older persons.
  - 30% have no usual source of care
  - Emergency department use is higher (despite access to insurance coverage)

Annals of Internal Medicine; Vol. 166 No. 4: 21 February 2017 J Adv Nursing; 2019; 75: 380-7

Patients Aren't Prepared

- Illness prevents them from becoming who they would like to become. Feeling of being "sick" first and "young" second.
  - "I don't like hospitals. I'm fed up because I've been coming here since I was very little. I'm fed up with the medicine. I've been traumatized by the pills"
- Encountering new situations – not sure how they affect their health condition
  - fatigue, health-risk behaviors (smoking, alcohol, drugs), stress, and sexuality
  - Despite perceptions to the contrary, young adults are surprisingly unhealthy: Rates of serious mental health conditions, unintentional injury, substance abuse, and sexually transmitted infections are high
- Regard health care as low priority vs. education, employment, housing, recreation, and relationships

Annals of Internal Medicine; Vol. 166 No. 4: 21 February 2017 J Adv Nursing; 2019; 75: 380-7

Ben was right


- 83% of youth with special needs and 86% of youth without special needs DO NOT meet national standards for health care transition
- Only 11% of adolescents with Down syndrome met the transition core outcome
  - Despite published AAP Health Supervision Guidelines for Down Syndrome with specific instructions to discuss transition

J Pediatr 2018;197:214-20

Cardiology is not any better

- CHD occurs in approximately 1 in 100 live births
  - Moderate or severe CHD occurs in 6/1000 live births
- 90% of patients with CHD will survive to adulthood
- Adults with CHD exceeded Children with CHD in 2000
  - Currently 2:1 ratio with >2.5 million adult CHD patients in North America/Europe
- Gaps in medical care occur in up to 70% of patients with CHD in US
  - lapses in care of >3 years in 21–61% of adult CHD patients who eventually return to cardiology care
    - Occurred in 30% in a single institution despite shared pediatric/adult clinic space

Cardiology is not any better

- CHD transition in Canada
  - Government mandated transfer of care at age 18
  - Universal Health care coverage

47% successfully transferred to Adult CHD program

The price we pay for poor transition

- Medical complications
- Medication noncompliance
- Discontinuity of care
- Patient dissatisfaction
- Higher emergency room/hospital use
- Higher costs of care

Pediatrics 2018; 142

How can we do better?

trans·fer

verb
'trans fər, transfər/

1. move from one place to another.
   "I went to sleep on the couch before transferring to my bedroom later in the night"
   synonyms: move, convey, shift, remove, take, carry, fetch, lift, bring, bear, conduct, send, pass on, transport, relay, change, relocate, resettle, transplant, uproot
   "the plants should be transferred into a tank"
2. change to another place, route, or means of transportation during a journey.
   "John advised him to transfer from Rome airport to the railroad station"

noun
/ tran(t)sfər/

1. an act of moving something or someone to another place.
   "a transfer of wealth to the poorer nations"
   synonyms: movement, move, moving, shifting, shift, handover, relocation, repositioning, transplant, redirection, conveyance, transferral, transference, removal, change, changeover, switch, conversion
   "he got a free transfer to a Spanish team"

Transfer of Care

GOAL is a discrete event- movement to a new health care setting and/or provider
- Occurs at age18, 21, or with geographic move

"Refer to adult cardiologist: Dr. _____. Best of luck with your new doctor!"

Possible interpretations
- "I'm finished taking care of you"
- "You're not my problem anymore"

tran·si·tion
/tran ziSH(ə)n,tran siSH(ə)n/

noun
noun: **transition**; plural noun: **transitions**

1. the process or a period of changing from one state or condition to another.
   "students **in transition** from one program to another"
   synonyms: change, move, passage, transformation, conversion, adaptation, adjustment, alteration, changeover, metamorphosis; More
   - the process by which a person permanently adopts the outward or physical characteristics of the gender with which they identify, as opposed to those associated with their birth sex. The process may or may not involve measures such as hormone therapy and gender reassignment surgery.
     "she had been living as a woman for eight years at that point and had completed her transition in 2001"
   - a passage in a piece of writing that smoothly connects two topics or sections to each other.
   - MUSIC
     a momentary modulation from one key to another.
   - PHYSICS
     a change of an atom, nucleus, electron, etc. from one quantum state to another, with emission or absorption of radiation

SOCIETY FOR ADOLESCENT MEDICINE

Transition from Child-Centered to Adult Health-Care Systems for Adolescents with Chronic Conditions

A Position Paper of the Society for Adolescent Medicine

Definition/Introduction

Transition is defined in this paper as the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health-care systems.

Transition of Care Guidelines – how we got here

- 2002 AAP/AAFP/ACP publish initial clinical guidelines for transition
- 2011 AAP/AAFP/ACP revised guidelines for transition
- 2015 Health Resources and Services Administration (HRSA)/Maternal Child Health Board (MCHB), Title V Services Block Grant Program – transition performance measure introduced
- 2018 AAP/AAFP/ACP revised guidelines for transition

Transition of Care

Goal is Patient / Family Readiness

- Should start early teens; occurs over years
- Started by pediatric providers, supported by parents
- Completed by adult providers and patient

Transition of Care

- Ideally it is:
  - Coordinated
  - Gradual
  - Flexible (acknowledge individual differences)
  - Addresses concerns of patients, family, and physician
  - Promotes patient autonomy, responsibility and adult life skills

Transition: Why is it important?

- Transition = growing up
- Transition to adulthood is important…
  - for patient growth
  - for patients to accept responsibility
  - for patients to become more independent and their own "medical advocate"
  - for patients to separate from Mom & Dad
  - for their pediatric MDs to hand over to adult subspecialists who are trained in adult medicine

Why is *transition* (growth) important?

- Society says: "We all have to grow up sometime."
- The pediatric cardiologist says: " 'I do not want to' or 'I feel uncomfortable' taking care of adults"
- The patient says: "I am an adult. And, I'm going to do adult things." *

*alcohol, tobacco, pregnancy, non-compliance, general recklessness, etc…

Transition is important and necessary

- Developmentally appropriate: young adults need preparation to manage own health care
- Adult docs/centers are appropriate providers of parts of health care: (eg reproductive / family planning, co-morbidities) & are more accustomed to dealing directly with patient
- We need to keep mission of pediatric hospital clear- are we a hospital for children or for childhood diseases?

Developing an effective transition program


PEDIATRICS
OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home

Patience H. White, W. Carl Cooley, TRANSITIONS CLINICAL REPORT AUTHORING GROUP, AMERICAN ACADEMY OF PEDIATRICS, AMERICAN ACADEMY OF FAMILY PHYSICIANS and AMERICAN COLLEGE OF PHYSICIANS

Pediatrics 2018;142;

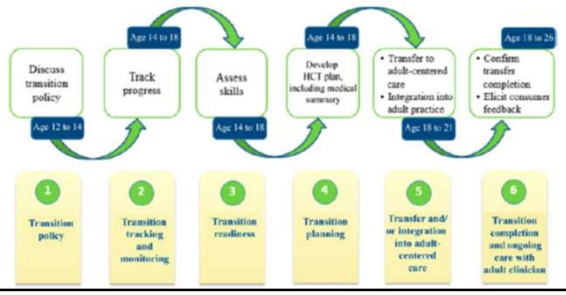
DOI: 10.1542/peds.2018-2587 originally published online October 22, 2018;

The online version of this article, along with updated information and services, is located on the World Wide Web at:
http://pediatrics.aappublications.org/content/142/5/e20182587

Clinician Education

- Med-Peds Program Directors Association have developed a transition curriculum
- Internal Medicine incorporating more rotations involving adolescents/young adults (colleges, etc) during Residency training
- Maintenance of Certification modules becoming more readily available

Six core elements of health care transition



Six core elements – Peds vs. Adult providers

Practice or provider	#1 Transition and/or care policy	#2 Tracking and monitoring	#3 Transition readiness and/or orientation to adult practice	#4 Transition planning and/or integration into adult approach to care or practice	#5 Transfer of care and/or initial visit	#6 Transition completion or ongoing care
Pediatric[a]	Create and discuss with youth and/or family	Track progress of youth and/or family transition preparation and transfer	Conduct transition readiness assessments	Develop transition plan, including needed readiness assessment skills and medical summary, prepare youth for adult approach to care, and communicate with new clinician	Transfer of care with information and communication including residual pediatric clinician's responsibility	Obtain feedback on the transition process and confirm young adult has been seen by the new clinician
Adult[a]	Create and discuss with young adult and guardian, if needed	Track progress of young adult's integration into adult care	Share and discuss welcome and FAQs with young adult and guardian, if needed	Communicate with previous clinician, ensure receipt of transfer package	Review transfer package, address young adult's needs and concerns at initial visit, update self-care assessment and medical summary	Confirm transfer completion with previous clinician, provide ongoing care with self-care skill building and link to needed specialists

Https://gottransition.org/index.cfm

- Got Transition/Center for Health Care Transition Improvement is a cooperative agreement between the Maternal and Child Health Bureau and The National Alliance to Advance Adolescent Health. Our aim is to improve transition from pediatric to adult health care through the use of new and innovative strategies for health professionals and youth and families. With a broad range of partners, we are working to:
  - Expand the use of the Six Core Elements of Health Care Transition™ in pediatric, family medicine, and internal medicine practices;
  - Partner with health professional training programs to improve knowledge and competencies in providing effective health care transition supports to youth, young adults, and families;
  - Develop youth and parent leadership in advocating for needed transition supports and participating in transition quality improvement efforts;
  - Promote health system measurement, performance, and payment policies aligned with the Six Core Elements of Health Care Transition; and
  - Serve as a clearinghouse for current transition information, tools, and resources.

Six core elements – Peds vs. Adult providers

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Sample transition policy statement

{Practice Name} is committed to helping our patients make a smooth transition from pediatric to adult health care. This process involves working with youth, beginning at ages 12 to 14, and their families to prepare for the change from a "pediatric" model of care where parents make most decisions to an "adult" model of care where youth take full responsibility for decision-making. This means that we will spend time during the visit with the teen without the parent present in order to assist them in setting health priorities and supporting them in becoming more independent with their own health care.

At age 18, youth legally become adults. We respect that many of our young adult patients choose to continue to involve their families in health care decisions. Only with the young adult's consent will we be able to discuss any personal health information with family members. If the youth has a condition that prevents him/her from making health care decisions, we encourage parents/caregivers to consider options for supported decision-making.

We will collaborate with youth and families regarding the age for transferring to an adult provider and recommend that this transfer occur before age 22. We will assist with this transfer process, including helping to identify an adult provider, sending medical records, and communicating with the adult provider about the unique needs of our patients.

As always, if you have any questions or concerns, please feel free to contact us.

Website: Gottransition.org

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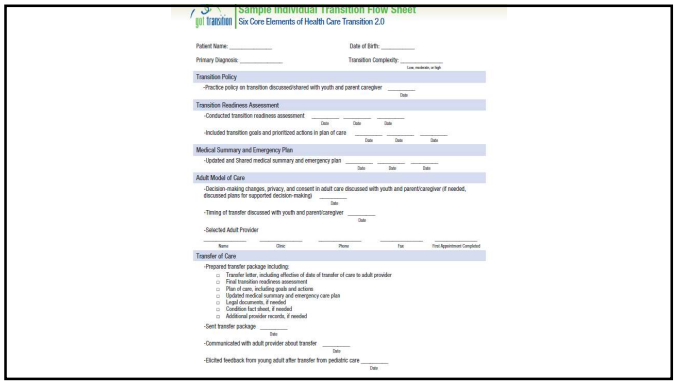


Sample Individual Transition Flow Sheet

Six Core Elements of Health Care Transition 2.0

Patient Name: _____ Date of Birth: _____

Primary Diagnosis: _____ Transition Complexity: _____ (Low, moderate, or high)

Transition Policy

-Practice policy on transition discussed/shared with youth and parent caregiver _____ (Date)

Transition Readiness Assessment

-Conducted transition readiness assessment _____ (Date) _____ (Date) _____ (Date)

-Included transition goals and prioritized actions in plan of care _____ (Date) _____ (Date) _____ (Date)

Medical Summary and Emergency Plan

-Updated and Shared medical summary and emergency plan _____ (Date) _____ (Date) _____ (Date)

Adult Model of Care

-Decision-making changes, privacy, and consent in adult care discussed with youth and parent/caregiver (if needed, discussed plans for supported decision-making) _____ (Date)

-Timing of transfer discussed with youth and parent/caregiver _____ (Date)

-Selected Adult Provider

_____ (Name) _____ (Clinic) _____ (Phone) _____ (Fax) _____ (First Appointment Completed)

Transfer of Care

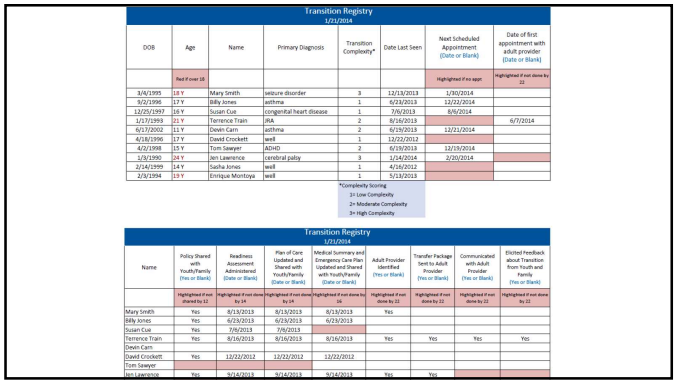
-Prepared transfer package including:

- ☐ Transfer letter, including effective of date of transfer of care to adult provider
- ☐ Final transition readiness assessment
- ☐ Plan of care, including goals and actions
- ☐ Updated medical summary and emergency care plan
- ☐ Legal documents, if needed
- ☐ Condition fact sheet, if needed
- ☐ Additional provider records, if needed

-Sent transfer package _____ (Date)

-Communicated with adult provider about transfer _____ (Date)

-Elicited feedback from young adult after transfer from pediatric care _____ (Date)



Transition Registry
1/21/2014

DOB	Age	Name	Primary Diagnosis	Transition Complexity*	Date Last Seen	Next Scheduled Appointment (Date or Blank)	Date of first appointment with adult provider (Date or Blank)
	Red if over 18					Highlighted if no appt	Highlighted if not done by 22
3/4/1995	18 Y	Mary Smith	seizure disorder	3	12/13/2013	1/30/2014	
9/2/1996	17 Y	Billy Jones	asthma	1	6/23/2013	12/22/2014	
12/25/1997	16 Y	Susan Cue	congenital heart disease	1	7/6/2013	8/6/2014	
1/17/1993	21 Y	Terrence Train	AIA	2	8/16/2013		6/7/2014
6/17/2002	11 Y	Devin Carn	asthma	2	6/19/2013	12/21/2014	
4/18/1996	17 Y	David Crockett	well	1	12/22/2012		
4/2/1998	15 Y	Tom Sawyer	ADHD	2	6/19/2013	12/19/2014	
1/3/1990	24 Y	Jen Lawrence	cerebral palsy	3	1/14/2014	2/20/2014	
2/14/1999	14 Y	Sasha Jones	well	1	4/16/2012		
2/3/1994	19 Y	Enrique Montoya	well	1	5/13/2013		

*Complexity Scoring
1= Low Complexity
2= Moderate Complexity
3= High Complexity

Transition Registry
1/21/2014

Name	Policy Shared with Youth/Family (Yes or Blank)	Readiness Assessment Administered (Date or Blank)	Plan of Care Updated and Shared with Youth/Family (Date or Blank)	Medical Summary and Emergency Care Plan Updated and Shared with Youth/Family (Date or Blank)	Adult Provider Identified (Yes or Blank)	Transfer Package Sent to Adult Provider (Yes or Blank)	Communicated with Adult Provider (Yes or Blank)	Elicited Feedback about Transition from Youth and Family (Yes or Blank)
	Highlighted if not shared by 12	Highlighted if not done by 14	Highlighted if not done by 14	Highlighted if not done by 14	Highlighted if not done by 22	Highlighted if not done by 22	Highlighted if not done by 22	Highlighted if not done by 22
Mary Smith	Yes	8/13/2013	8/13/2013	8/13/2013	Yes			
Billy Jones	Yes	6/23/2013	6/23/2013	6/23/2013				
Susan Cue	Yes	7/6/2013	7/6/2013					
Terrence Train	Yes	8/16/2013	8/16/2013	8/16/2013	Yes	Yes	Yes	Yes
Devin Carn								
David Crockett	Yes	12/22/2012	12/22/2012	12/22/2012				
Tom Sawyer								
Jen Lawrence	Yes	9/14/2013	9/14/2013	9/14/2013	Yes	Yes		

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Transition Readiness standardized scorable tools

- Transition Readiness Assessment Questionnaire (TRAQ)
  - https://www.etsu.edu/com/pediatrics/traq/default.php
- Am I ON TRAC for Adult Care questionanaire
  - http://www.bcchildrens.ca/transition-to-adult-care/Documents/Am%20I%20ON%20TRAC%20For%20Adult%20Care%20Youth%20Questionnaire.pdf
- UNC TR(x)ANSITION scale
  - https://gottransition.org/resourceGet.cfm?id=126
- STARx questionnaire
  - https://www.acponline.org/system/files/documents/clinical_information/high_value_care/clinician_resources/pediatric_adult_care_transitions/neph_endstage_renal/starx_questionnaire_patients_adolescent_version.pdf
- TRANSITION-Q
  - https://onlinelibrary.wiley.com/doi/epdf/10.1111/cch.12207

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Sample Plan of Care

got transition | Six Core Elements of Health Care Transition 2.0

Instructions: This sample plan of care is a written document developed jointly with the transitioning youth to establish priorities and a course of action that integrates health and personal goals. Motivational interviewing and strength-based counseling are key approaches in developing a collaborative process and shared decision-making. Information from the transition readiness assessment can be used to guide the development of health goals. The plan of care should be dynamic and updated regularly and sent to the new adult provider as part of the transfer package along with the latest transition readiness assessment, medical summary and emergency care plan, and, if needed, a condition fact sheet and legal documents.

Name: Date of Birth:

Primary Diagnosis: Secondary Diagnosis:

What matters most to you as you become an adult? How can learning more about your health condition and how to use health care support your goals?

Prioritized Goals	Issues or Concerns	Actions	Person Responsible	Target Date	Date Complete

Initial Date of Plan: _____ Last Updated: _____ Parent/Caregiver Signature: _____

Clinician Signature: Care Staff Contact: Care Staff Phone:

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Children's Healthcare of Atlanta | Sibley Heart Center Cardiology

Sample Transfer of Care Checklist

got transition | Six Core Elements of Health Care Transition 2.0

Patient Name: _____ Date of Birth: _____

Primary Diagnosis: _____ Transition Complexity: _____
Low, moderate, or high

-Prepared transfer package including:

- □ Transfer letter, including effective of date of transfer of care to adult provider
- □ Final transition readiness assessment
- □ Plan of care, including transition goals and pending actions
- □ Updated medical summary and emergency care plan
- □ Guardianship or health proxy documents, if needed
- □ Condition fact sheet, if needed
- □ Additional provider records, if needed

-Sent transfer package _____
Date

-Communicated with adult provider about transfer _____
Date

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got transition

Sample Health Care Transition Feedback Survey for Youth

Six Core Elements of Health Care Transition 2.0

This is a survey about your experience changing from pediatric to adult health care. You may choose to answer this survey or not. Your responses to this survey are confidential.

1. How often did your previous health care provider explain things in a way that was easy to understand?
   ☐ Always ☐ Usually ☐ Sometimes ☐ Never
2. How often did your previous health care provider listen carefully to you?
   ☐ Always ☐ Usually ☐ Sometimes ☐ Never
3. Did your previous health care provider respect how your customs or beliefs affect your care?
   ☐ A lot ☐ Some ☐ A little ☐ Not at all
4. Did your previous health care provider discuss with you or have an office policy that informed you at what age you may need to change to a new provider who treats mostly adults?
   ☐ Yes ☐ No
5. Did you talk with your previous health care provider without your parent or guardian in the room?
   ☐ Yes ☐ No
6. Did your previous health care provider actively work with you to gain skills to manage your own health and health care (e.g., know your medications and their side effects, know what to do in an emergency)?*
   ☐ A lot ☐ Some ☐ A little ☐ Not at all
7. Did your previous health care provider actively work with you to think about and plan for the future (e.g., take time to discuss future plans about education, work, relationships, and development of independent living skills)?*
   ☐ A lot ☐ Some ☐ A little ☐ Not at all
8. How often did you schedule your own appointments with your previous health care provider?
   ☐ Never ☐ Sometimes ☐ Usually ☐ Always
9. Did your previous health care provider explain legal changes in privacy, decision-making, and consent that take place at age 18?
   ☐ Yes ☐ No
10. Did your previous health care provider actively work with you to create a written plan to meet your health goals and needs?*
    ☐ Yes ☐ No
11. Did your previous health care provider create and share with you your medical summary?
    ☐ Yes ☐ No
12. Did your previous health care provider have information about community resources?
    ☐ Yes ☐ No
13. Do you know how you will be insured as you become an adult?*
    ☐ Yes ☐ No
14. Did your previous health care provider assist you in identifying a new adult provider to transfer to?
    ☐ Yes ☐ No
15. Did your adult health care provider have your medical records before your first visit?
    ☐ Yes ☐ No ☐ Don't Know ☐ Have not had first visit yet
16. Did you feel prepared to change to an adult health care provider?
    ☐ Very prepared ☐ Somewhat prepared ☐ Not prepared
17. At what age did you change to an adult health care provider?

    Age _____
18. How could your pediatric health care provider have made your move to an adult health care provider better?

Thank you.

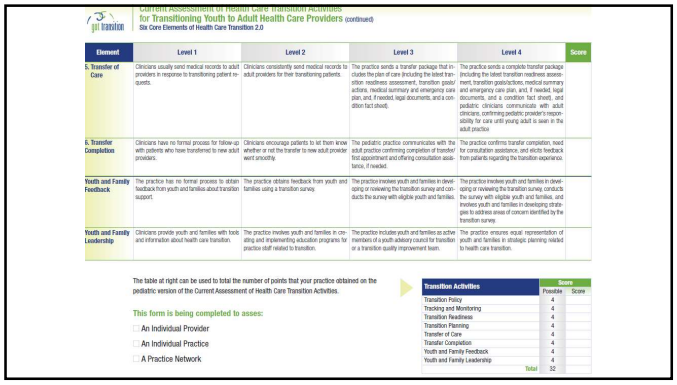
*Adapted from the National Survey of Children's Health

got transition

Current Assessment of Health Care Transition Activities for Transitioning Youth to Adult Health Care Providers

Six Core Elements of Health Care Transition 2.0

Element	Level 1	Level 2	Level 3	Level 4	Score
1. Transition Policy	Clinicians vary in their approach to health care transition, including the appropriate age for transfer to adult providers.	Clinicians follow a uniform but not a written policy about the age for transfer. The approach for transition planning differs among clinicians.	The practice has a written transition policy or approach, developed with input from youth and families that includes privacy and consent information and addresses the practice's transition approach and age of transfer. The policy is not consistently shared with youth and families.	The practice has a written transition policy or approach, developed with input from youth and families that includes privacy and consent information, a description of the practice's approach to transition, and age of transfer. Clinicians discuss it with youth and families beginning at ages 12 to 14. The policy is publicly posted and familiar to all staff.	
2. Transition Tracking and Monitoring	Clinicians vary in the identification of transitioning youth, but most wait until close to the age of transfer to identify and prepare youth.	Clinicians use patient records to document certain relevant transition information (e.g., future provider information, date of transfer).	The practice has an individual transition flow sheet or registry for identifying and tracking transitioning youth, ages 14 and older, or a subgroup of youth with chronic conditions as they progress through and complete some but not all transition processes.	The practice has an individual transition flow sheet or registry for identifying and tracking transitioning youth, ages 14 and older, or a subgroup of youth with chronic conditions as they progress through and complete all "Six Core Elements of Health Care Transition 2.0," using EHR if possible.	
3. Transition Readiness	Clinicians vary in terms of the age when youth begin to have time alone during preventive visits without the parent/caregiver present. Transition readiness is seldom assessed.	Clinicians consistently offer time alone for youth after age 14 during preventive visits without the parent/caregiver present. They usually want to assess transition readiness/self- care skills close to the time of transfer.	The practice consistently offers clinician time alone with youth after age 14 with clinicians during preventive visits, and clinicians discuss transition readiness/self-care skills and changes in adult-centered care beginning at ages 14 to 16, but no formal assessment tool is used.	The practice consistently offers clinician time alone with youth after age 14 during preventive visits. Clinicians use a standardized transition readiness assessment tool. Self-care needs and goals are incorporated into the youth's plan of care beginning at ages 14 to 16.	
4. Transition Planning	Clinicians vary in addressing health care transition needs and goals. They seldom make available a plan of care (including medical summary and emergency care plan and transition goals and action steps) or a list of adult providers.	Clinicians consistently address transition needs and goals as part of the plan of care. They usually provide a list of adult providers close to the time of transfer.	The practice partners with youth and families in developing and updating their plan of care with prioritized transition goals and preferences for securing an adult provider. This plan of care is regularly updated and accessible to youth and families.	The practice has incorporated transition into its plan of care template for all patients. All clinicians are encouraged to partner with youth and families in developing transition goals and updating and sharing the plan of care. Clinicians address needs for decision-making supports prior to age 18. The practice has a vetted list of adult providers and assists youth in identifying adult providers.	



Current Assessment of Health Care Transition Activities
for Transitioning Youth to Adult Health Care Providers (continued)
Six Core Elements of Health Care Transition 2.0

Element	Level 1	Level 2	Level 3	Level 4	Score
5. Transfer of Care	Clinicians usually send medical records to adult providers in response to transitioning patient requests.	Clinicians consistently send medical records to adult providers for their transitioning patients.	The practice sends a transfer package that includes the plan of care (including the latest transition readiness assessment, transition goals/actions, medical summary and emergency care plan, and, if needed, legal documents, and a condition fact sheet).	The practice sends a complete transfer package (including the latest transition readiness assessment, transition goals/actions, medical summary and emergency care plan, and, if needed, legal documents, and a condition fact sheet), and pediatric clinicians communicate with adult clinicians, confirming pediatric provider's responsibility for care until young adult is seen in the adult practice	
6. Transfer Completion	Clinicians have no formal process for follow-up with patients who have transferred to new adult providers.	Clinicians encourage patients to let them know whether or not the transfer to new adult provider went smoothly.	The pediatric practice communicates with the adult practice confirming completion of transfer/first appointment and offering consultation assistance, if needed.	The practice confirms transfer completion, need for consultation assistance, and elicits feedback from patients regarding the transition experience.	
Youth and Family Feedback	The practice has no formal process to obtain feedback from youth and families about transition support.	The practice obtains feedback from youth and families using a transition survey.	The practice involves youth and families in developing or reviewing the transition survey and conducts the survey with eligible youth and families.	The practice involves youth and families in developing or reviewing the transition survey, conducts the survey with eligible youth and families, and involves youth and families in developing strategies to address areas of concern identified by the transition survey.	
Youth and Family Leadership	Clinicians provide youth and families with tools and information about health care transition.	The practice involves youth and families in creating and implementing education programs for practice staff related to transition.	The practice includes youth and families as active members of a youth advisory council for transition or a transition quality improvement team.	The practice ensures equal representation of youth and families in strategic planning related to health care transition.	

The table at right can be used to total the number of points that your practice obtained on the pediatric version of the Current Assessment of Health Care Transition Activities.

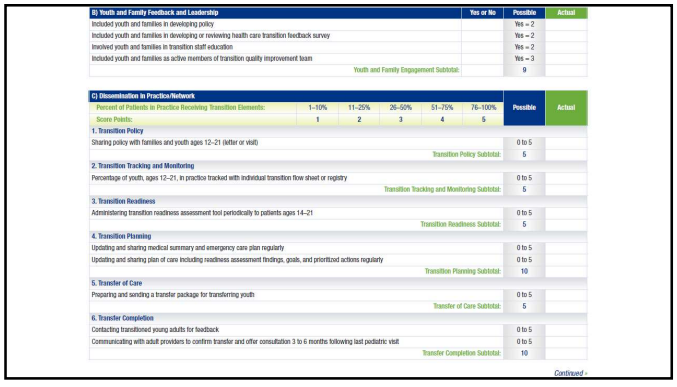
This form is being completed to asses:

- An Individual Provider
- An Individual Practice
- A Practice Network

Transition Activities	Score	
	Possible	Score
Transition Policy	4	
Tracking and Monitoring	4	
Transition Readiness	4	
Transition Planning	4	
Transfer of Care	4	
Transfer Completion	4	
Youth and Family Feedback	4	
Youth and Family Leadership	4	
Total	32	

A) Implementation in Practice/Network	Yes or No	Possible	Actual	Possible Documentation
1. Transition Policy				
Developed a written transition policy/statement that describes the practice's approach to transition		Yes = 4		Transition policy
Included information about privacy and consent at age 18 in transition policy/statement		Yes = 2		Transition policy
Posted policy/statement (public clinic spaces, practice website etc.)		Yes = 2		Photo
Educated staff about transition policy/statement and their role in transition process		Yes = 2		Date(s) of program
Designated practice staff to incorporate *Six Core Elements* into clinical processes		Yes = 4		Job description
Transition Policy Subtotal:		14		
2. Transition Tracking and Monitoring				
Established criteria and process for identifying transitioning target population and entering into individual transition flow sheet or registry		Yes = 3		Screenshot or copy of registry/list
Incorporated transition core elements into clinical processes (e.g. EHR templates, progress notes, care plans)		Yes = 4		Screenshot or copy of chart
Tracking and Monitoring Subtotal:		7		
3. Transition Readiness				
Adopted transition readiness assessment tool for use in practice		Yes = 4		Readiness assessment
Incorporated transition readiness assessment into clinical processes		Yes = 3		Clinical process flow sheet
Transition Readiness Subtotal:		7		
4. Transition Planning				
Developed a plan of care template that incorporates transition readiness assessment findings, goals, and prioritized actions		Yes = 4		Sample plan of care
Established clinical process to assess need for decision-making support before age 18		Yes = 2		Practice policy
Developed a medical summary and emergency care plan		Yes = 4		Portable medical summary
Made available list of community support resources		Yes = 2		List of resources
Established process to match and communicate with selected adult provider		Yes = 2		Practice policy
Transition Planning Subtotal:		14		
5. Transfer of Care				
Adopted a self-care assessment tool for use in practice		Yes = 4		Transfer package checklist
Developed a medical summary and emergency care plan templates		Yes = 2		Transfer letter
Transfer of Care Subtotal:		6		
6. Transfer Completion				
Have mechanism to systematically obtain feedback from young adult about transition process		Yes = 3		Survey or interview questions
Transfer Completion Subtotal:		3		

Continued ›



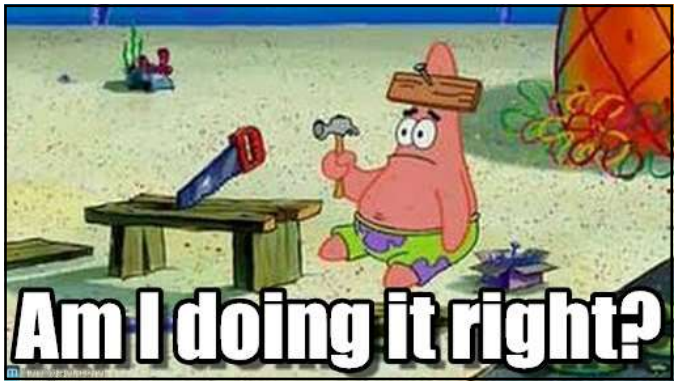
B) Youth and Family Feedback and Leadership	Yes or No	Possible	Actual
Included youth and families in developing policy		Yes = 2	
Included youth and families in developing or reviewing health care transition feedback survey		Yes = 2	
Involved youth and families in transition staff education		Yes = 2	
Included youth and families as active members of transition quality improvement team		Yes = 3	
Youth and Family Engagement Subtotal:		9	

C) Dissemination in Practice/Network							
Percent of Patients in Practice Receiving Transition Elements:	1–10%	11–25%	26–50%	51–75%	76–100%	Possible	Actual
Score Points:	1	2	3	4	5		
1. Transition Policy							
Sharing policy with families and youth ages 12–21 (letter or visit)						0 to 5	
Transition Policy Subtotal:						5	
2. Transition Tracking and Monitoring							
Percentage of youth, ages 12–21, in practice tracked with individual transition flow sheet or registry						0 to 5	
Transition Tracking and Monitoring Subtotal:						5	
3. Transition Readiness							
Administering transition readiness assessment tool periodically to patients ages 14–21						0 to 5	
Transition Readiness Subtotal:						5	
4. Transition Planning							
Updating and sharing medical summary and emergency care plan regularly						0 to 5	
Updating and sharing plan of care including readiness assessment findings, goals, and prioritized actions regularly						0 to 5	
Transition Planning Subtotal:						10	
5. Transfer of Care							
Preparing and sending a transfer package for transferring youth						0 to 5	
Transfer of Care Subtotal:						5	
6. Transfer Completion							
Contacting transitioned young adults for feedback						0 to 5	
Communicating with adult providers to confirm transfer and offer consultation 3 to 6 months following last pediatric visit						0 to 5	
Transfer Completion Subtotal:						10	

Continued ›

The table below can be used to total the number of points that your practice obtained in implementation of the *Six Core Elements*, youth and family engagement, and dissemination.

	1. Transition Policy		2. Tracking & Monitoring		3. Transition Readiness		4. Transition Planning		5. Transfer of Care		6. Transfer Completion		Total Score	
	Possible	Score	Possible	Score	Possible	Score	Possible	Score	Possible	Score	Possible	Score	Possible	Score
Implementation in Practice/Network	14		7		7		14		6		3		51	
Youth and Family Feedback and Leadership	—	—	—	—	—	—	—	—	—	—	—	—	9	
Dissemination in Practice/Network	5		5		5		10		5		10		40	
Total	**19**		**12**		**12**		**24**		**11**		**13**		**100**	



Current Assessment of Health Care Transition Activities for Transitioning Youth to Adult Health Care Providers
Six Core Elements of Health Care Transition 2.0

Element	Level 1	Level 2	Level 3	Level 4	Score
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3. Transition Readiness	Clinicians vary in terms of the age when youth begin to have time alone during preventive visits without the parent/caregiver present. Transition readiness is not formally assessed. ✓	Clinicians consistently offer time alone for youth after age 14 during preventive visits without the parent/caregiver present. They usually wait to assess transition readiness/self- care skills close to the time of transfer.	The practice consistently offers clinician time alone with youth after age 14 with clinicians during preventive visits, and clinicians discuss transition readiness/self-care skills and changes in adult-centered care beginning at ages 14 to 16, but no formal assessment tool is used.	The practice consistently offers clinician time alone with youth after age 14 during preventive visits. Clinicians use a standardized transition readiness assessment tool. Self-care needs and goals are incorporated into the youth's plan of care beginning at ages 14 to 16.	
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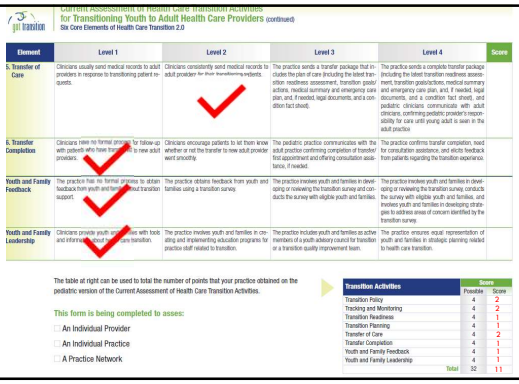

Current Assessment of Health Care Transition Activities
for Transitioning Youth to Adult Health Care Providers (continued)
Six Core Elements of Health Care Transition 2.0

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Youth and Family Leadership	Clinicians provide youth and families with tools and information about transition.	The practice involves youth and families in creating and implementing education programs for practice staff related to transition.	The practice includes youth and families as active members of a youth advisory council for transition or a transition quality improvement team.	The practice ensures equal representation of youth and families in strategic planning related to health care transition.	

The table at right can be used to total the number of points that your practice obtained on the pediatric version of the Current Assessment of Health Care Transition Activities.

This form is being completed to asses:

- An Individual Provider
- An Individual Practice
- A Practice Network

Transition Activities	Score	
	Possible	Score
Transition Policy	4	2
Tracking and Monitoring	4	2
Transition Readiness	4	1
Transition Planning	4	1
Transfer of Care	4	2
Transfer Completion	4	1
Youth and Family Feedback	4	1
Youth and Family Leadership	4	1
Total	32	11

Sibley Heart Center Cardiology Transition Process

- Insert CHD conditions which need ACHD
- Start at age 13
- EPIC screenshots for adolescent tips
- Transfer process

- How do we score on AAP/ACP/AFP metrics?

Sibley Heart Center Cardiology Transition Process

Group 1
Simple Congenital Heart Disease
These patients can usually be cared for in the general medical community

Native Conditions:
Isolated congenital aortic valve disease
Isolated congenital mitral valve disease
(except parachute valve, cleft leaflet)
Isolated patent foramen ovale or small atrial septal defect
(no associated lesions)
Mild pulmonic stenosis

Repaired conditions:
Previously ligated or occluded ductus arteriosus
Repaired secundum or sinus venosus
Atrial septal defect without residua
Repaired ventricular septal defect without residua

Group 2
Congenital Heart Disease of Moderate Severity
These patients should be seen periodically at adult congenital heart disease centers.

Aortic-left ventricular fistulae
Anomalous pulmonary venous drainage (partial or total)
Atrioventricular canal defects (partial or complete)
Bicuspid Aortic Valve
Coarctation of the aorta
Ebstein's anomaly
Infundibular right ventricular outflow obstruction of significance
Ostium primum atrial septal defect
Patent ductus arteriosus – (not closed)
Pulmonary valve regurgitation (moderate to severe)
Sinus of Valsalva fistula/aneurysm
Sinus venosus atrial septal defect
Subvalvar or supravalvar aortic stenosis (except HOCM)
Tetralogy of Fallot Ventricular septal defect with Aortic regurgitation Coarctation of the aorta Mitral Disease
Right ventricular outflow tract obstruction
Unrepaired tricuspid / mitral valve
Subaortic stenosis

HOCM = Hypertrophic obstructive cardiomyopathy

Group 3
Congenital Heart Disease of Great Complexity
These patients should be seen regularly at adult congenital heart disease centers

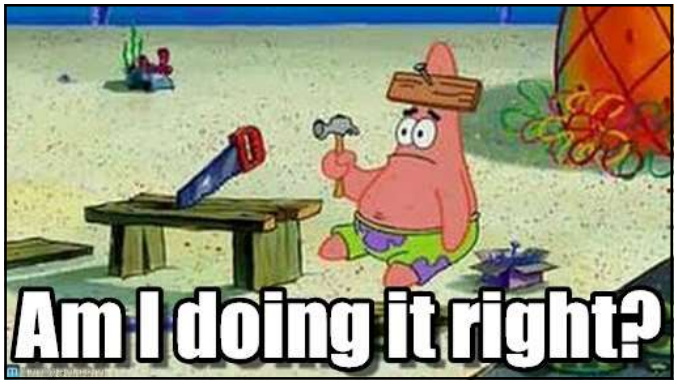
Conduit, valved or nonvalved
Cyanotic congenital heart (all forms)
Double-outlet ventricle
Ebstein/anger syndrome
Fontan procedure
Mitral Atresia
Single ventricle (also double inlet or outlet, common or primitive
Pulmonary atresia (all forms)
Pulmonary vascular obstructive diseases
Transposition of the great arteries
Congenitally Corrected Transposition of the great artes
Tricuspid atresia
Truncus arteriosus / hemitruncus
Other abnormalities of atrioventricular or ventriculoarterial connection not included above (i.e. crisscross

Sibley Heart Center Cardiology Transition Process

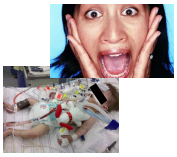
- Start at age 12 and review transition issues annually at follow-up visits
- Documented in EMR
- Transfer process
  - EMR order "Refer to Adult Congenital Heart Clinic"
    - Places them automatically on the "lost to follow-up" list
  - Once they attend first appointment at ACHD, we are notified – removed from "lost to follow-up" list
  - If no notification from ACHD, patient is contacted by our group (phone call/mail)

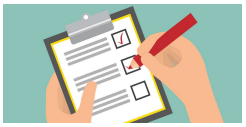
Sibley Heart Center Cardiology Transition Process

Our EMR process for Adolescent Management



Sibley Heart Center Cardiology Transition Process





11/32

Barriers to successful transition

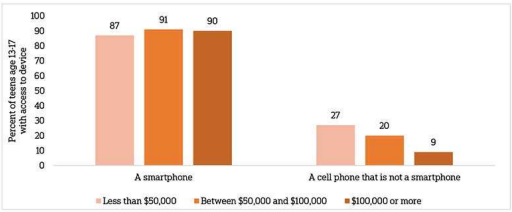
TABLE 1 Youth, Young Adult, and Family Transition[27,28,37,59,65–84]

- Fear of a new health care system and/or hospital
  - Not wanting to leave their pediatric clinician and pediatric institution
  - Anxiety about how to relinquish control around managing their youth condition
  - Anxiety of not knowing the adult clinicians, adult health care system, and logistical issues (ie, finding parking, making appointments, finding a physician who is taking new patients, inadequate transferring patient records, and insurance issues)
  - Changing and/or different therapies recommended in adult health care
  - Families' fear that adult clinicians will not listen to and value their expertise
  - Negative beliefs about adult health care
- Inadequate planning
  - Inadequate preparation and support from clinicians on the transition process and adult model of care
  - Not having seen clinician alone
  - Youth and young adults less interested in health compared with broader life circumstances
  - Adolescents' age, sex, and race and/or ethnicity and their parents' socioeconomic status can affect transition preparation
- System difficulties
  - Lack of communication and coordination and transfer of medical records between adult and pediatric clinician or system
  - Limited availability of adult primary and specialty clinicians
  - Difficulty in locating adult clinicians who have specialized knowledge about and community resources for youth with pediatric-onset chronic diseases
  - Loss of insurance coverage among young adults and cost of care barriers

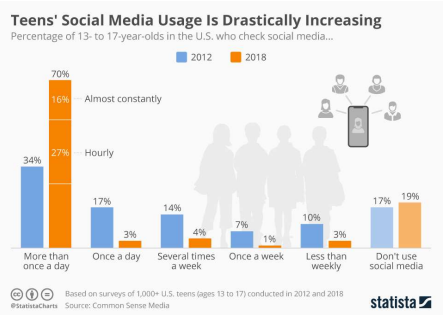
Pediatrics 2018; 142

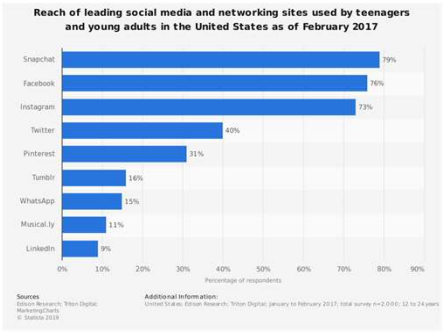
Social Media

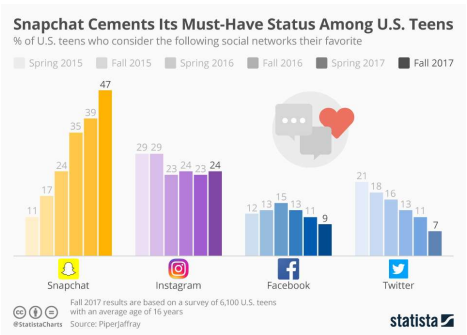
While smartphone use is high across all income brackets, lower-income teens are more likely to have access to cell phones that are not smartphones.



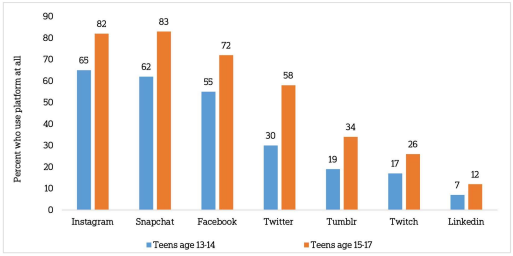
Question: Do you, personally, have or have access to each of the following items, or not?
Source: AP-NORC Center poll conducted December 7-31, 2016, with 790 teenagers age 13-17 nationwide


Teens' Social Media Usage Is Drastically Increasing
Percentage of 13- to 17-year-olds in the U.S. who check social media...
2012
2018
Almost constantly
Hourly
34%
70%
16%
27%
17%
3%
14%
4%
7%
1%
10%
3%
17%
19%
More than once a day
Once a day
Several times a week
Once a week
Less than weekly
Don't use social media
Based on surveys of 1,000+ U.S. teens (ages 13 to 17) conducted in 2012 and 2018
@StatistaCharts
Source: Common Sense Media
statista


Reach of leading social media and networking sites used by teenagers and young adults in the United States as of February 2017
Snapchat
Facebook
Instagram
Twitter
Pinterest
Tumblr
WhatsApp
Musical.ly
LinkedIn
79%
76%
73%
40%
31%
16%
15%
11%
9%
0%
10%
20%
30%
40%
50%
60%
70%
80%
90%
Percentage of respondents
Sources
Additional Information:

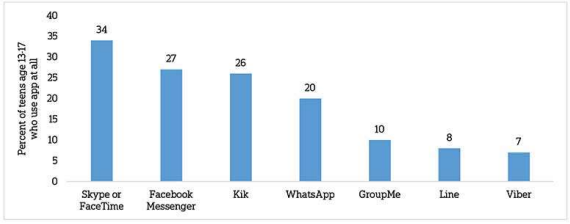

Snapchat Cements Its Must-Have Status Among U.S. Teens
% of U.S. teens who consider the following social networks their favorite
Spring 2015
Fall 2015
Spring 2016
Fall 2016
Spring 2017
Fall 2017
11
17
24
35
39
47
29
29
23
24
23
24
12
13
15
13
11
9
21
18
16
13
11
7
Snapchat
Instagram
Facebook
Twitter
Fall 2017 results are based on a survey of 6,100 U.S. teens with an average age of 16 years
@StatistaCharts
Source: Piperjaffray
statista

Older teens are more active on social media, using each of these platforms more than their younger counterparts.



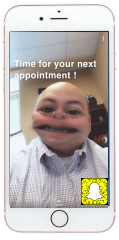
Question: How often do you use the following, if at all?
Source: AP-NORC Teen Survey December 2016. n=790 with teenagers age 13-17 nationwide

Skype, FaceTime, Facebook Messenger, Kik, and WhatsApp are the most popular messaging apps among teens.

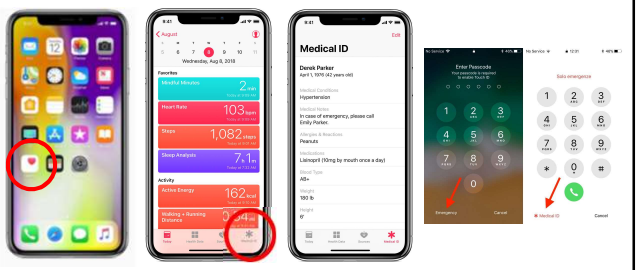


Question: How often do you use the following, if at all?
Source: AP-NORC Center poll conducted December 7-31, 2016, with 790 teenagers age 13-17 nationwide

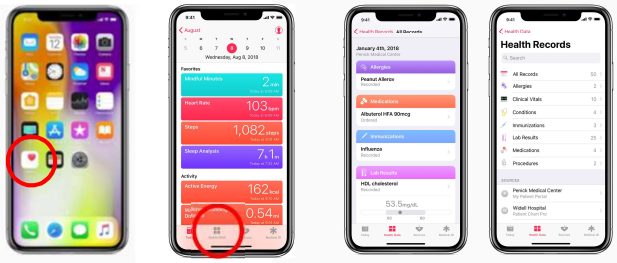
We have to speak their language



Emergency Medical ID on phones



Medical records on phones



Medical records on phones

- FHIR (Fast Healthcare Interoperability Resources)
  - Able to integrate various EMRs
  - Web based
- Over 130 major health systems have joined in less than one year

What can you do to get started?

- Focus group of providers and/or of patients/families- find out problems with status quo and vision of future
- Collect data for your program/institution
- Private time with adolescent patient at each visit
- Address Policy & Procedure- clear mission, culture, plan
- Staff education
- Begin conversations with adult providers
- Write transition/ developmental expectation timelines

What can you do to get started?

- Educational and PR material- what message are you sending?
- Start database
- Joint care conferences/educational session
- Passport health care summary
- Readiness checklist
- Graduation certificate
- Coordination through "Office of transition"
- Medical ID/Records on phone

Conclusions

- Transition of care (instead of transfer of care), should be our goal when preparing adolescent patients for adulthood
- We can do better!
- There are many challenges to a successful transition, but many resources are now available to better prepare ourselves and our patients

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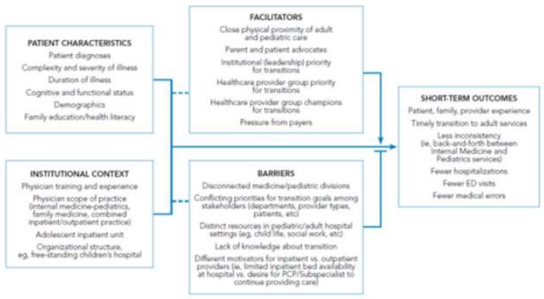
Inpatient transfer process



Inpatient transfer process

- Survey of 96 US Children's Hospitals
  - 10% had adolescent unit
  - 38% had inpatient transition initiative
    - 31% with a set policy
    - 19% with a transition leader
    - 11% had both
  - Those with outpatient transition processes more often had inpatient initiative
    - 79% vs. 29%
- CF Foundation has developed an inpatient transfer guideline
  - Less adults with CF admitted to CH despite more living with the condition

Medically complex patients

- Youth with medical complexity = 1% of all US children
- Multiple medical conditions = multiple specialists = multiple transitions
  - Best done sequentially
- Limited social function
  - Need to discuss legal guardian/custodian, medical power of attorney
  - Legal consultation with a disability lawyer
  - Tax advice regarding special needs trust fund
  - Social work consultation to discuss available resources