Assessment of Transition Plan Implementation and Provider Engagement Among Adults Living with Spinal Muscular Atrophy (SMA): Findings from a Cross-Sectional Survey

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Supplemental Table 1. Anticipated age of transition and perceived helpfulness of resources among respondents who had not yet initiated transition to adult care.

Question, n (%)	Transition planning not initiated n = 15
Planned age at transition at time of survey	
Age 18 to 20	2 (13.3)
Age 21 to 24	6 (40.0)
Age 25 to 29	4 (26.7)
Not planning to transition to adult care	1 (6.7)
Unknown	2 (13.3)
Would you like to initiate discussions with your pediatric providers, regarding the transition to adult care?	
Yes	4 (26.7)
No	2 (13.3)
Unsure at this time	9 (60.0)
Would the creation of a transition plan with your pediatric healthcare providers be helpful to the process?	
Yes	9 (60.0)
No	3 (20.0)
Unsure at this time	3 (20.0)
Would educational materials (brochures, handouts, or online materials) be helpful as you consider the transition planning process?	
Yes	11 (73.3)
No	3 (20.0)
Unsure	1 (6.7)

Supplemental Table 2. Education, household income, and employment status of all respondents.

Characteristic, n (%)	All respondents N = 137	Transition planning initiated or completed[a]		Transition planning not initiated
		Excellent/ Very good/Good n = 78	Fair/Poor n = 44	n = 15
Highest level of education				
High school or less	40 (29.2)	20 (25.6)	13 (29.5)	7 (46.7)
Some college, vocational training, or associate's degree	39 (28.5)	28 (35.9)	8 (18.2)	3 (20.0)
Bachelor's or higher degree	58 (42.3)	30 (38.5)	23 (52.3)	5 (33.3)
Household annual pretax income				
Less than $20,000	30 (21.9)	14 (17.9)	12 (27.3)	4 (26.7)
$21,000 to $40,000	13 (9.5)	7 (9.0)	6 (13.6)	0 (0)
$41,000 to $70,000	29 (21.2)	16 (20.5)	11 (25.0)	2 (13.3)
$71,000 to $100,000	24 (17.5)	15 (19.2)	8 (18.2)	1 (6.7)
Greater than $100,000	13 (9.5)	7 (9.0)	1 (2.3)	5 (33.3)
Don't know	28 (20.4)	19 (24.4)	6 (13.6)	3 (20.0)
Employment status				
Employed full-time	35 (25.5)	19 (24.4)	13 (29.5)	3 (20.0)
Employed part-time	30 (21.9)	17 (21.8)	11 (25.0)	2 (13.3)
Not employed; seeking employment	27 (19.7)	20 (25.6)	5 (11.4)	2 (13.3)
Not employed; not seeking employment	45 (32.8)	22 (28.2)	15 (34.1)	8 (53.3)

[a] Inclusive of individuals that are preparing to transition to adult care, preparing to transition with adult consults initiated, partially transitioned, or fully transitioned to adult care (see Table 2).

Supplemental Table 3. Structured planning exposure among respondents who initiated or completed the transition to adult care.

Respondent exposure to elements of structured provider-led transition planning, n (%)	All respondents[a] N = 122			Excellent/Very good/Good n = 78			Fair/Poor n = 44		
	Yes	No	Don't recall	Yes	No	Don't recall	Yes	No	Don't recall
Discussion of transition planning and/or development of a transition plan	53 (43.4)	51 (41.8)	18 (14.8)	40 (51.3)	25 (32.1)	13 (16.7)	13 (17.8)	26 (35.6)	5 (6.8)
Transition readiness assessment	27 (22.1)	63 (51.6)	32 (26.2)	22 (28.2)	33 (42.3)	23 (29.5)	5 (6.8)	30 (41.1)	9 (12.3)
Receipt of transition plan[b]	8 (15.1)	24 (45.3)	21 (39.6)	7 (17.5)	17 (42.5)	16 (40.0)	1 (7.7)	7 (53.8)	5 (38.5)
Receipt of transition-related educational materials	22 (18.0)	73 (59.8)	27 (22.1)	19 (24.4)	40 (51.3)	19 (24.4)	3 (6.8)	33 (75.0)	8 (18.2)
Self-management guidance	34 (27.9)	60 (49.2)	28 (23.0)	26 (33.3)	32 (41.0)	20 (25.6)	8 (18.2)	28 (63.6)	8 (18.2)
Guidance on healthcare-related legal changes	29 (23.8)	70 (57.4)	23 (18.9)	23 (29.5)	42 (53.8)	13 (16.7)	6 (13.6)	28 (63.6)	10 (22.7)
Preliminary visits with adult healthcare providers[c]									
Adult primary care provider	50 (47.6)	46 (43.8)	9 (8.6)	40 (60.6)	21 (31.8)	5 (7.6)	10 (25.6)	25 (64.1)	4 (10.3)
Adult neurologist	49 (46.7)	50 (47.6)	6 (5.7)	35 (53.0)	28 (42.4)	3 (4.5)	14 (35.9)	22 (56.4)	3 (7.7)
Adult pulmonologist	39 (37.1)	57 (54.3)	9 (8.6)	31 (47.0)	31 (47.0)	4 (6.1)	8 (20.5)	26 (66.7)	5 (12.8)
Adult PM&R specialist	16 (15.2)	80 (76.2)	9 (8.6)	15 (22.7)	47 (71.2)	4 (6.1)	1 (2.6)	33 (84.6)	5 (12.8)

[a]Inclusive of individuals that are preparing to transition to adult care, preparing to transition with adult consults initiated, partially transitioned, or fully transitioned to adult care

[b]Only respondents were those who answered "Yes" to "Did you and/or your parents discuss with your pediatric provider decisions about transition to adult care and/or development of a transition plan?"

[c]Only asked of those who have initiated consults, partially transitioned, or fully transitioned.

Supplementary File 1: Cure SMA 2021 Adult Transition Survey

Page exit logic: Skip / Disqualify Logic **IF:** ((#1 Question "In what country do you currently reside?" is one of the following answers ("Other - Write In") OR #2 Question "Current Age" is greater than "29") OR #2 Question "Current Age" is less than "18") **THEN:** Disqualify and display: "Sorry, you do not qualify to take this survey."

1) In what country do you currently reside?*

( ) United States
( ) Other - Write In: _____

Validation: Must be numeric Max character count = 2

2) Current Age*

_____

Module 1: Demographics

3) First Name*

_____

4) Last Name*

_____

5) Street Address:*

_____

6) City:*

_____

Validation: Max character count = 2 Min character count = 2

7) State/Province:*

_____

Validation: Must be numeric Max character count = 6

8) Zip Code:*

_____

Validation: %s format expected

9) Email:*

Please note, gift card to be sent to email provided

_____

Validation: **Min. answers = 1** *(if answered)*

10) Primary Phone Number:*

Cell Phone: _____
Home phone: _____

11) Date of Birth:*

Please enter as mm/dd/yy

_____

12) Sex:*

( ) Male
( ) Female
( ) Non-binary
( ) Prefer not to answer

13) What is your race? If mixed, please choose Other*

( ) Asian
( ) Native Hawaiian or Other Pacific Islander
( ) Black/African-American
( ) White
( ) Hispanic/Latino
( ) American Indian/Alaska Native
( ) Other - Write In: _____
( ) Prefer not to answer

14) What is your ethnic origin?*

( ) Hispanic or Latinx
( ) Not Hispanic or Latinix

15)

What is the primary language spoken in your home?

***

( ) English
( ) Spanish
( ) Any other language
( ) Don't know
( ) Refused

16)

Are you currently enrolled in school and/or home schooled?

*

( ) Yes, I am currently enrolled in school.
( ) Yes, I am currently being home schooled.
( ) No, I am not currently enrolled in school and/or in a homeschool program.
( ) No, I am not currently enrolled, but plan to enroll within the next year.

17)

What is the highest degree or level of school you have completed? (If currently enrolled, highest degree received. If homeschooled, chose the grade equivalent.)

*

( ) Some high school, no diploma
( ) High school graduate, diploma or the equivalent (for example: GED)
( ) Some college credit, no degree
( ) Trade/technical/vocational training
( ) Associate degree (for example: AA, AS)
( ) Bachelor's degree (for example: BA, BS)
( ) Master’s degree (for example: MA, MS)
( ) Doctorate degree (for example: MD, PhD)

18)

What is your total household annual pretax income?

*

( ) Less than $20,000
( ) $21,000 to $40,000
( ) $41,000 to $70,000
( ) $71,000 to $100,000
( ) $101,000 to $150,000
( ) $151,000 to $200,000
( ) Greater than $200,000
( ) Don't know

19) Type of SMA*

( ) Type 0
( ) Type I
( ) Type II
( ) Type III
( ) Type IV
( ) Distal
( ) Kennedy's
( ) SMARD (distal hereditary motor, HMN6)
( ) Unknown

20) How many SMN2 Copies do you have?*

( ) 1
( ) 2
( ) 3
( ) 4
( ) 5 or more
( ) Don't know

Validation: **Min. answers = 14** *(if answered)*

21) Have you EVER been diagnosed or been told by a doctor that you have any of the following conditions?*

	Yes	No	Don't Know
Anxiety	( )	( )	( )
Asthma	( )	( )	( )
Chronic Respiratory Failure	( )	( )	( )
Contractures	( )	( )	( )
Covid-19	( )	( )	( )
Depression	( )	( )	( )
Diabetes	( )	( )	( )
Hydrocephalus	( )	( )	( )
Hyperlipidemia	( )	( )	( )
Hypertension	( )	( )	( )
Obesity	( )	( )	( )
Scoliosis	( )	( )	( )

Sleep apnea/hypoventilation/sleep disordered breathing	( )	( )	( )
Tonsillitis	( )	( )	( )

22)

Are you currently employed?

( ) Yes, I am employed full-time
( ) Yes, I am employed part-time
( ) No, I am not employed but seeking full-time employment
( ) No, I am not employed but seeking part-time employment
( ) No, I am not employed and am not seeking employment

Validation: **Min. answers = 7** *(if answered)*

23) What type of health insurance do you have?*

	Yes	**No**	**Don't Know**
Medicare	( )	( )	( )
Medicaid	( )	( )	( )
Employer-based	( )	( )	( )
Through marketplace (ACA)	( )	( )	( )
Tricare	( )	( )	( )
VA or CHAMPVA	( )	( )	( )
I do not have insurance	( )	( )	( )

(untitled)

Page exit logic: Skip / Disqualify Logic**IF:** #24 Question "Which of the following best describes your current interaction with pediatric and adult healthcare provider(s)?" is one of the following answers ("I continue to see my pediatric health care providers; I have not initiated discussions with providers regarding the transition to adult care") **THEN:** Jump to page 8 - Module 5: Anticipated Engagement with Pediatric Providers Regarding Preparation and Planning for the Transition from Pediatric to Adult Care

Logic: Show/hide trigger exists.

24) Which of the following best describes your current interaction with pediatric and adult healthcare provider(s)?*

( ) I continue to see my pediatric health care providers; I have not initiated discussions with providers regarding the transition to adult care
( ) I continue to see my pediatric health care providers; we have begun preparing/planning for the transition to adult care
( ) I continue to see my pediatric health care providers; we have begun preparing/planning for the transition to adult care and have initiated consults with adult providers
( ) I partially transitioned to adult healthcare providers; I continue to see a few pediatric healthcare providers
( ) I have fully transitioned to adult healthcare providers

Logic: Hidden unless: #24 Question "Which of the following best describes your current interaction with pediatric and adult healthcare provider(s)?" is one of the following answers ("I have fully transitioned to adult healthcare providers")

25) At what age did you transition to adult healthcare providers?*

( ) Age 18 to 20
( ) Age 21 to 24
( ) Age 25 to 29
( ) I don't know

Validation: **Min. answers = 4** *(if answered)*
Logic: Hidden unless: #24 Question "Which of the following best describes your current interaction with pediatric and adult healthcare provider(s)?" is one of the following answers ("I partially transitioned to adult healthcare providers; I continue to see a few pediatric healthcare providers")

26) Which of the following pediatric health care providers do you continue to see?*

	Yes	No
Pediatrician	( )	( )
General Practitioner	( )	( )
Pediatric neurologist	( )	( )
Pediatric pulmonologist	( )	( )

Validation: **Min. answers = 5** *(if answered)*
Logic: Hidden unless: #24 Question "Which of the following best describes your current interaction with pediatric and adult healthcare provider(s)?" is one of the following answers ("I continue to see my pediatric health care providers; we have begun preparing/planning for the transition to adult care","I continue to see my pediatric health care providers; we have begun preparing/planning for the transition to adult care and have initiated consults with adult providers")

27) If you are ill and require a hospital stay, what type of hospital are you admitted to?*

	Yes	No
Community hospital	( )	( )
Tertiary care hospital with neuromuscular treatment services	( )	( )
SMA Treatment Center	( )	( )
Children's hospital	( )	( )
Rehabilitation hospital	( )	( )

Logic: Show/hide trigger exists. Hidden unless: #24 Question "Which of the following best describes your current interaction with pediatric and adult healthcare provider(s)?" is one of the following answers ("I continue to see my pediatric health care providers; we have begun preparing/planning for the transition to adult care","I continue to see my pediatric health

care providers; we have begun preparing/planning for the transition to adult care and have initiated consults with adult providers")

28) At what age do you plan to fully transition to adult healthcare providers?*

( ) Age 18 to 20
( ) Age 21 to 24
( ) Age 25 to 29
( ) Age 30 or above
( ) Not planning to transition to adult care
( ) Unknown

Validation: Min = 30 Max = 50 Must be numeric Max character count = 2
Logic: Hidden unless: #28 Question "At what age do you plan to fully transition to adult healthcare providers?" is one of the following answers ("Age 30 or above")

29) If you plan to transition at age 30 or above, please indicate the age you plan to transition:

_____

Module 2: Engagement with Pediatric Providers and Assessment of the Transition Planning Process

Please answer the next few questions to reflect your previous experiences with pediatric healthcare providers

30) Which pediatric healthcare provider is / was responsible for your transition to adult healthcare?
*****

( ) Pediatrician
( ) General Practitioner
( ) Pediatric neurologist
( ) Pediatric pulmonologist
( ) Physical medicine and rehabilitation specialist
( ) Nurse practitioner
( ) Social worker
( ) Clinical coordinator

( ) N/A; Self coordinated transition
( ) Other - Write In: _____

31) Did your pediatric healthcare provider ask questions to assess your transition readiness?
A transition readiness assessment is a questionnaire that providers and families can use to assess youths' ability to make appointments, to understand their medications and to develop other skills needed for transition to adult care*.

( ) Yes
( ) No
( ) Don't recall

Logic: Show/hide trigger exists.

32) Did you and/or your parents discuss with your pediatric provider decisions about transition to adult care and/or development of a transition plan?
A transition plan helps an individual / family prepare for the shift from pediatric to adult care. Transition planning includes the identification of adult practitioners and services, dates of transfer from pediatric to adult healthcare providers, goals established by the patient/family, and barriers to achieving goals ***

( ) Yes
( ) No
( ) Don't recall

Logic: Hidden unless: #32 Question "Did you and/or your parents discuss with your pediatric provider decisions about transition to adult care and/or development of a transition plan?
A transition plan helps an individual / family prepare for the shift from pediatric to adult care. Transition planning includes the identification of adult practitioners and services, dates of transfer from pediatric to adult healthcare providers, goals established by the patient/family, and barriers to achieving goals **" is one of the following answers ("No","Don't recall")**

33) Please indicate what items were discussed with your pediatric providers as you prepare(d) to shift to adult care.

_____
_____
_____

_____

Logic: Hidden unless: #32 Question "Did you and/or your parents discuss with your pediatric provider decisions about transition to adult care and/or development of a transition plan? ***A transition plan helps an individual / family prepare for the shift from pediatric to adult care. Transition planning includes the identification of adult practitioners and services, dates of transfer from pediatric to adult healthcare providers, goals established by the patient/family, and barriers to achieving goals*** **" is one of the following answers ("No","Don't recall")**

34) Please check the items below that you think should be addressed and included within the transition plan:
A transition plan helps an individual / family prepare for the shift from pediatric to adult care. Transition planning includes the identification of adult practitioners and services, dates of transfer from pediatric to adult healthcare providers, goals established by the patient/family, and barriers to achieving goals
*****

	Yes	No
SMA diagnosis and management	( )	( )
The optimal timing of your transfer from pediatric to adult healthcare for both primary and subspecialty care	( )	( )
A summary of your healthcare issues	( )	( )
Identified healthcare goals	( )	( )
Outlined steps necessary to achieve the goals	( )	( )
Potential barriers or	( )	( )

obstacles to the identified goals		
Your preferences for adult service requirements – the range of options to consider for your healthcare or treatment	( )	( )
Reproductive choices	( )	( )
Emergency plans	( )	( )
Advanced plan of care (e.g., medical power of attorney, living will, do not resuscitate order)	( )	( )
Mental health / well being resources	( )	( )

Logic: Show/hide trigger exists. Hidden unless: #32 Question "Did you and/or your parents discuss with your pediatric provider decisions about transition to adult care and/or development of a transition plan?
A transition plan helps an individual / family prepare for the shift from pediatric to adult care. Transition planning includes the identification of adult practitioners and services, dates of transfer from pediatric to adult healthcare providers, goals established by the patient/family, and barriers to achieving goals **" is one of the following answers ("Yes")**

35) Did you receive a copy of the transition plan?*

( ) Yes
( ) No
( ) Don't recall

Validation: **Min. answers = 11** *(if answered)*

Logic: Hidden unless: #35 Question "Did you receive a copy of the transition plan?" is one of the following answers ("Yes")

36) Please check the items below that were included within the transition plan:*

	Yes	No	Don't recall
SMA diagnosis and management	( )	( )	( )
The optimal timing of your transfer from pediatric to adult healthcare for both primary and subspecialty care	( )	( )	( )
A summary of your healthcare issues	( )	( )	( )
Identified healthcare goals	( )	( )	( )
Outlined steps necessary to achieve the goals	( )	( )	( )
Potential barriers or obstacles to the identified goals	( )	( )	( )
Your preferences for adult service requirements – the range of options to consider for your healthcare or treatment	( )	( )	( )
Reproductive choices	( )	( )	( )

Emergency plans	( )	( )	( )
Advanced plan of care (e.g., medical power of attorney, living will, do not resuscitate order)	( )	( )	( )
Mental health /well being resources	( )	( )	( )

Logic: Show/hide trigger exists. Hidden unless: #32 Question "Did you and/or your parents discuss with your pediatric provider decisions about transition to adult care and/or development of a transition plan?
A transition plan helps an individual / family prepare for the shift from pediatric to adult care. Transition planning includes the identification of adult practitioners and services, dates of transfer from pediatric to adult healthcare providers, goals established by the patient/family, and barriers to achieving goals **" is one of the following answers ("Yes")**

37) Did your pediatric healthcare provider discuss with you and/or your parent, your identified goals, as outlined in the transition plan?*

( ) Yes
( ) No
( ) Don't recall

Validation: **Min. answers = 4** *(if answered)*
Logic: Hidden unless: #37 Question "Did your pediatric healthcare provider discuss with you and/or your parent, your identified goals, as outlined in the transition plan?" is one of the following answers ("Yes")

38) Please indicate which healthcare goals in the transition plan were discussed:*

	Yes	**No**	**Don't recall**
Increasing knowledge of SMA	( )	( )	( )

Building mastery of self-management skills	( )	( )	( )
Building mastery of self-advocacy skills	( )	( )	( )
Adapting to changes during puberty	( )	( )	( )

Logic: Show/hide trigger exists.

39) Did your pediatric healthcare provider offer educational materials (brochures, handouts, or online materials) to address your specific areas of concern regarding the transition planning process?*

( ) Yes
( ) No
( ) Don't recall

Validation: **Min. answers = 5** *(if answered)*
Logic: Hidden unless: #39 Question "Did your pediatric healthcare provider offer educational materials (brochures, handouts, or online materials) to address your specific areas of concern regarding the transition planning process?" is one of the following answers ("Yes")

40) Please indicate the specific areas that were included:*

	Yes	**No**	**Don't recall**
The importance of shifting to adult providers	( )	( )	( )
The differing healthcare needs of adults	( )	( )	( )
Health insurance retention	( )	( )	( )
Self-care management information,	( )	( )	( )

including communicating your care needs to your caregiver			
Community support services (peer groups, peer mentoring, seminars)	( )	( )	( )

Logic: Show/hide trigger exists.

41) Did your pediatric healthcare provider offer guidance on how to self-manage your care?*

( ) Yes
( ) No
( ) Don't recall

Validation: **Min. answers = 10** *(if answered)*
Logic: Hidden unless: #41 Question "Did your pediatric healthcare provider offer guidance on how to self-manage your care?" is one of the following answers ("Yes")

42) Please indicate the specific areas of guidance provided:*

	Yes	**No**	**Don't recall**
How to contact your providers	( )	( )	( )
Where to go or call when your doctor's office is closed.	( )	( )	( )
How to access your emergency care plan	( )	( )	( )
Making your own doctor and therapy appointments	( )	( )	( )
Knowing how often you need	( )	( )	( )

to see your healthcare providers.			
Knowing how to contact your pharmacy and what to do if you run out of medicines.	( )	( )	( )
Knowing the names, dosage, and how to take your prescription medications.	( )	( )	( )
Knowing what medications you should not take and what you are allergic to	( )	( )	( )
Knowing where to get a blood test or x-rays if the doctor orders them	( )	( )	( )
Contacting the healthcare provider about unusual changes in your health (e.g., allergic reactions, infections).	( )	( )	( )

Logic: Show/hide trigger exists.

43) Did your pediatric providers help you understand healthcare-related legal changes that occur with the transition to adulthood?
*****

( ) Yes
( ) No

( ) Don't recall

Validation: **Min. answers = 3** *(if answered)*
Logic: Hidden unless: #43 Question "Did your pediatric providers help you understand healthcare-related legal changes that occur with the transition to adulthood? " is one of the following answers ("Yes")

44) Please indicate which health care related legal changes were discussed:*

	Yes	No	Don't recall
Changes in who can access your health information	( )	( )	( )
Changes in decision-making (privacy and consent)	( )	( )	( )
Changes in insurance (e.g., how long you remain on parents' insurance plan, how to obtain your own insurance plan)	( )	( )	( )

Logic: Hidden unless: #24 Question "Which of the following best describes your current interaction with pediatric and adult healthcare provider(s)?" is one of the following answers ("I continue to see my pediatric health care providers; we have begun preparing/planning for the transition to adult care and have initiated consults with adult providers","I partially transitioned to adult healthcare providers; I continue to see a few pediatric healthcare providers","I have fully transitioned to adult healthcare providers")

45) Did you and/or your parents have preliminary visits with any of the following adult healthcare providers:*

	Yes	No	Don't recall
Adult primary care provider	( )	( )	( )
Adult neurologist	( )	( )	( )
Adult pulmonologist	( )	( )	( )
Adult physical medicine and rehabilitation specialist (physiatrist)	( )	( )	( )

46) Overall, how would you rate your experience with the transition process from pediatric to adult care?*

( ) Excellent
( ) Very good
( ) Good
( ) Fair
( ) Poor

47) In your opinion, how can providers improve the transition process from pediatric care to adult?*

	Yes	No
Encourage greater involvement of adolescents and families in the transition planning process	( )	( )
Initiate the transition planning process at an earlier age.	( )	( )
Have discussions about the	( )	( )

differences between pediatric and adult care		
Initiate annual discussions about the transition process (e.g., best timing for the transfer from pediatric to adult care, disease self-management, healthcare specific goals)	( )	( )
Facilitate meetings with adult healthcare providers prior to the transfer to adult care	( )	( )
Provide educational materials that describe and support the transition process	( )	( )
Provide access to comprehensive overviews of my medical history	( )	( )

Page entry logic: This page will show when: #24 Question "Which of the following best describes your current interaction with pediatric and adult healthcare provider(s)?" is one of the following answers ("I continue to see my pediatric health care providers; we have begun preparing/planning for the transition to adult care and have initiated consults with adult providers")

Module 3: Engagement with Adult Healthcare Providers (Consults Only)

48) Please describe any formal or informal support group and/or resources for support you may have had during your transition from pediatric to adult care.

_____
_____
_____
_____

Logic: Show/hide trigger exists.

49) Have you experienced any challenges when consulting with adult healthcare providers?*

( ) Yes, I have had some major challenges when consulting with my adult providers.
( ) Yes, I have had some minor challenges when consulting with my adult providers.
( ) No, I have not had challenges when consulting with my adult providers.
( ) N/A, I have not consulted with my adult providers

Validation: **Min. answers = 11** *(if answered)*
Logic: Hidden unless: #49 Question "Have you experienced any challenges when consulting with adult healthcare providers?" is one of the following answers ("Yes, I have had some major challenges when consulting with my adult providers.","Yes, I have had some minor challenges when consulting with my adult providers.")

50) Please indicate the types of challenges you have had during pre-transition consultations:*

	Yes	**No**
Appointment and treatment scheduling	( )	( )
Ability to locate local adult provider(s)	( )	( )
Navigating the adult healthcare system	( )	( )
Involvement in care decisions	( )	( )
Access to clinicians with experience in SMA	( )	( )

Access to mental health / well being resources	( )	( )
Adult healthcare provider's knowledge of SMA	( )	( )
Adult healthcare provider responsiveness to my specific questions or concerns during consultation visits	( )	( )
Time spent with adult providers with whom I have consulted	( )	( )
Communication or cultural issues with my adult healthcare providers with whom I have consulted	( )	( )
Insurance-related issues	( )	( )

Validation: **Min. answers = 8** *(if answered)*

51) Please indicate opportunities to optimize your experience with adult healthcare providers during pre-transition consultations:*

	Yes	**No**
Provide additional time with adult providers	( )	( )
Facilitate communication with my current healthcare providers	( )	( )

Provide additional educational materials and resources for adult related healthcare issues (e.g., insurance, legal, etc.)	( )	( )
Increase peer mentoring / network opportunities	( )	( )
Increase partnering with my providers regarding my healthcare decisions	( )	( )
Increase communication options for follow up care such as MyChart	( )	( )
Ease of scheduling options	( )	( )
Provide additional assistance in locating local adult providers	( )	( )

Page entry logic: This page will show when: #24 Question "Which of the following best describes your current interaction with pediatric and adult healthcare provider(s)?" is one of the following answers ("I partially transitioned to adult healthcare providers; I continue to see a few pediatric healthcare providers","I have fully transitioned to adult healthcare providers")

Module 4: Engagement with Adult Healthcare Providers (Partial / Full Transition to Adult Care)

52) Please describe any formal or informal support group and/or resources for support you may have had during your transition from pediatric to adult care.*

_____
_____
_____
_____

53) After transitioning to adult healthcare, did your adult healthcare provider utilize your transition plan when establishing care?*

( ) Yes
( ) No
( ) Don't recall

Validation: **Min. answers = 12** *(if answered)*

54) Please indicate in the chart below how frequently you have received any of the following services in the last 24 months (either in a clinic or via telemedicine).*

	Weekly	**Every two weeks**	**Monthly**	**Every two months**	**Twice a year**	**Once a year**	**I have not engaged with them in the past 24 months**	**I do not utilize these services**
Primary care (e.g., Internal Medicine, Family Medicine, OB/Gyn,	( )	( )	( )	( )	( )	( )	( )	( )
Adult Neurology	( )	( )	( )	( )	( )	( )	( )	( )
Orthopedic services	( )	( )	( )	( )	( )	( )	( )	( )
Rehabilitation services	( )	( )	( )	( )	( )	( )	( )	( )
Physical therapy services	( )	( )	( )	( )	( )	( )	( )	( )

Pulmonology / respiratory therapy services	( )	( )	( )	( )	( )	( )	( )	( )
Cardiology services	( )	( )	( )	( )	( )	( )	( )	( )
Speech therapy services	( )	( )	( )	( )	( )	( )	( )	( )
Nutritional care / dietician services	( )	( )	( )	( )	( )	( )	( )	( )
Mental health / well being / support groups	( )	( )	( )	( )	( )	( )	( )	( )
Social work / resource access support	( )	( )	( )	( )	( )	( )	( )	( )
Emergency services	( )	( )	( )	( )	( )	( )	( )	( )

Validation: **Min. answers = 7** *(if answered)*

55) If you answered in the question above, that you have not engaged with adult providers in the last 24 months, please share your reasons below:*

	Yes	**No**
My disease is stable	( )	( )
I have a low perceived value of healthcare	( )	( )
I am more isolated due to physical limitations (e.g., driving,	( )	( )

wheelchair, etc.)		
I have difficulty accessing or navigating the adult healthcare system.	( )	( )
I have difficulty accessing or locating adult providers.	( )	( )
I mistrust adult providers	( )	( )
I have insurance issues	( )	( )

56) If you have disengaged with adult healthcare providers and/or have less satisfaction with adult SMA care, please explain why.

_____
_____
_____
_____

57) Overall, how would you rate your current relationship with your adult healthcare providers?
*****

( ) Excellent
( ) Very good
( ) Good
( ) Fair
( ) Poor

Logic: Show/hide trigger exists.

58) Have you had any challenges when consulting with adult healthcare providers?*

( ) Yes, I have had some major challenges when consulting with my adult providers.
( ) Yes, I have had some minor challenges when consulting with my adult providers.
( ) No, I have not had challenges when consulting with my adult providers.

Validation: **Min. answers = 12** *(if answered)*
Logic: Hidden unless: #58 Question "Have you had any challenges when consulting with adult healthcare providers?" is one of the following answers ("Yes, I have had some major challenges when consulting with my adult providers.","Yes, I have had some minor challenges when consulting with my adult providers.")

59) Please indicate the types of challenges you have had: *

	Yes	No
Appointment scheduling	( )	( )
Ability to locate local adult providers	( )	( )
Navigating the adult healthcare system	( )	( )
Access to clinicians with experience in SMA	( )	( )
Involvement in care decisions	( )	( )
Access to mental health / well being resources	( )	( )
Adult healthcare providers' knowledge of SMA.	( )	( )
Adult healthcare providers' responsiveness to	( )	( )

my specific questions or concerns during visits		
Time spent with my adult providers.	( )	( )
Communication between my adult providers.	( )	( )
Communication or cultural issues with my adult providers.	( )	( )
Insurance related issues	( )	( )

Validation: **Min. answers = 7** *(if answered)*

60) Please indicate opportunities to optimize your experience with your adult providers: *

	Yes	**No**
Provide additional time with my healthcare providers	( )	( )
Facilitate communication between my healthcare providers	( )	( )
Provide additional educational materials and resources for adult related healthcare issues (e.g., insurance, legal, etc.)	( )	( )
Increase peer mentoring /	( )	( )

network opportunities		
Increase partnering with my providers regarding my healthcare decisions	( )	( )
Increase communication options for follow up care such as MyChart	( )	( )
Ease of scheduling options	( )	( )

Page entry logic: This page will show when: #24 Question "Which of the following best describes your current interaction with pediatric and adult healthcare provider(s)?" is one of the following answers ("I continue to see my pediatric health care providers; I have not initiated discussions with providers regarding the transition to adult care")

Module 5: Anticipated Engagement with Pediatric Providers Regarding Preparation and Planning for the Transition from Pediatric to Adult Care

Please answer the next few questions to reflect your expectations of pediatric healthcare providers regarding your transfer to adult care

Logic: Show/hide trigger exists.

61) At what age do you plan to fully transition to adult healthcare providers?
*****

( ) Age 18 to 20
( ) Age 21 to 24
( ) Age 25 to 29
( ) Age 30 or above
( ) Not planning to transition to adult care
( ) Unknown

Validation: Min = 30 Max = 50 Must be numeric Max character count = 2
**Logic: Hidden unless: #61 Question "At what age do you plan to fully transition to adult healthcare providers?
" is one of the following answers ("Age 30 or above")**

62) If you you selected 'Age 30 or above', please specify age:*

_____

63) Would you like to initiate discussions with your pediatric providers, regarding the transition to adult care?
***

( ) Yes
( ) No
( ) Unsure at this time

64) What areas would you like to discuss with your pediatric providers regarding the transition to adult care?

_____
_____
_____
_____

Logic: Show/hide trigger exists.

65) Would the creation of a transition plan with your pediatric healthcare providers be helpful to the process?
A transition plan helps an individual / family prepare for the shift from pediatric to adult care. Transition planning includes the identification of adult practitioners and services, dates of transfer from pediatric to adult healthcare providers, goals established by the patient/family, and barriers to achieving goals
***

( ) Yes
( ) No

( ) Unsure at this time

Validation: **Min. answers = 12** *(if answered)*
Logic: Hidden unless: #65 Question "Would the creation of a transition plan with your pediatric healthcare providers be helpful to the process?
A transition plan helps an individual / family prepare for the shift from pediatric to adult care. Transition planning includes the identification of adult practitioners and services, dates of transfer from pediatric to adult healthcare providers, goals established by the patient/family, and barriers to achieving goals
" is one of the following answers ("Yes")

66) Please identify what items you would like to incorporate within your transition plan:
A transition plan helps an individual / family prepare for the shift from pediatric to adult care. Transition planning includes the identification of adult practitioners and services, dates of transfer from pediatric to adult healthcare providers, goals established by the patient/family, and barriers to achieving goals
*****

	Yes	No
SMA diagnosis and management	( )	( )
The optimal timing of their transfer from pediatric to adult healthcare for both primary and subspecialty care	( )	( )
A summary of their healthcare issues	( )	( )
Identified healthcare goals	( )	( )
Outlined steps necessary to achieve the goals	( )	( )
Potential barriers or	( )	( )

obstacles to the identified goals		
Your preferences for adult service requirements – the range of options to consider for their healthcare or treatment	( )	( )
Reproductive choices	( )	( )
Emergency plans	( )	( )
Advanced plan of care (e.g., medical power of attorney, living will, do not resuscitate order)	( )	( )
Mental health / well being resources	( )	( )
None of the above	( )	( )

Logic: Show/hide trigger exists.

67) Would educational materials (brochures, handouts, or online materials) be helpful as you consider the transition planning process?
*****

( ) Yes
( ) No
( ) Unsure

Validation: **Min. answers = 5** *(if answered)*

Logic: Hidden unless: #67 Question "Would educational materials (brochures, handouts, or online materials) be helpful as you consider the transition planning process? " is one of the following answers ("Yes")

68) Please identify what materials you would like to receive:*

	Yes	No
The importance of shifting to adult providers	( )	( )
The differing healthcare needs of adults	( )	( )
Health insurance changes	( )	( )
Self-care management information, including communicating their care needs to their caregiver	( )	( )
Community support services (e.g., peer groups, peer mentoring, seminars, etc.)	( )	( )

Validation: **Min. answers = 7** *(if answered)*

69) In your opinion, how can providers improve the transition process from pediatric to adult care?
*****

	Yes	No
Encourage greater involvement of adolescents and families in the transition planning process	( )	( )

Initiate the transition planning process at an earlier age.	( )	( )
Have discussions about the differences between pediatric and adult care	( )	( )
Initiate annual discussions about the transition process (e.g., best timing for the transfer from pediatric to adult care, disease self-management, healthcare specific goals)	( )	( )
Facilitate meetings with adult healthcare providers prior to the transfer to adult care	( )	( )
Provide educational materials that describe and support the transition process	( )	( )
Provide access to comprehensive overviews of my medical history	( )	( )