

## SUPPORTING INFORMATION

This **confidential online research survey** will take approximately 5-15 minutes to complete and focuses on the models of care being used to care for your survivors of childhood cancer who are adult-age ( $\geq 21$  years) and, if applicable, their transition of survivorship care from a pediatric-centered to an adult-centered model of care. All collected data will be reported collectively in aggregate to ensure confidentiality. Please answer questions to the best of your ability to be reflective of most providers at your institution as we realize practices may vary from individual to individual.

The following are key definitions for selected terms used in the survey:

- A **childhood cancer survivor** is defined as anyone diagnosed with a cancer prior to the age of 21 years who is at least 5 years from diagnosis.
- **Survivorship care** is defined as the delivery of services that include targeted screening for late-effects based on therapeutic exposures, management of complications related to cancer treatment, health education, and psychosocial support.
- **Pediatric-centered care** is a model that focuses on interactions with both the patient and the parent/caregiver. It is typically delivered by pediatric providers in a pediatric clinical setting. Much of the healthcare responsibility is shared between the patient and the parent/caregiver.
- **Adult-centered care** is a model that primarily focuses on adult medical issues through interactions primarily with the patient. This may be delivered by an adult or a pediatric provider and typically occurs in an adult clinical setting in a developmentally appropriate way. The healthcare responsibility is primarily assumed by the patient.
- **Transition of survivorship care** is defined as process over time where the survivor is transferred from a pediatric-centered model of care to an adult-centered model of care.

Before starting the survey, please have the following information:

1. number of children diagnosed with a new cancer at your institution each year
2. number of visits per week or per year in your childhood cancer survivor program (if such a program exists)

### Please provide the following information

1. Please provide your COG institution name: \_\_\_\_\_
2. Please provide the following information
  - a. Last Name: \_\_\_\_\_
  - b. First Name: \_\_\_\_\_
  - c. Role (physician, nurse practitioner, nurse, coordinator, psychologist, social worker, research assistant, nurse coordinator, etc): \_\_\_\_\_
  - d. Email address: \_\_\_\_\_

## SUPPORTING INFORMATION

3. Approximately how many new pediatric oncology patients (< 21 years old) are diagnosed each year at your institution?
  - a. <50
  - b. 50-100
  - c. 101-150
  - d. 151-200
  - e. 201-250
  - f. >250
  
4. Which of the following best describes the geographic location of your institution's adult medical providers (either primary care or subspecialists)?
  - a. same medical campus
  - b. separate medical campus at a completely different geographic location
  - c. our institution does not have adult medical providers
  - d. Other: \_\_\_\_\_
  
5. Does your institution have a specialized childhood cancer survivorship/late-effects program with a designated provider(s) or program leader?
  - a. Yes
  - b. No

If answer is a. Yes → #6. If answer is b. No → #11.

6. Approximately how many childhood cancer survivorship visits occur at your institution **each year** in the specialized survivorship/late-effects program?
  - a. <50
  - b. 50-100
  - c. 101-300
  - d. 301-500
  - e. 501-800
  - f. >800
  - g. I do not know

If answer is g. I do not know → #7, all other answers → #8

7. Approximately how many childhood cancer survivor visits occur at your institution **each week** in the specialized survivorship/late-effects program?
  - a. >5
  - b. 6-15
  - c. 16-30
  - d. >30
  - e. I do not know

## SUPPORTING INFORMATION

8. Which of the following professionals make up the clinical team that is routinely present and available during each visit to deliver **pediatric-centered** (as defined above) survivorship care? (check all that apply)
- MD/DO
  - NP
  - PA
  - RN
  - Nutritionist
  - Social Worker
  - Psychologist
  - Trainee (fellow/resident/medical student)
  - Other: \_\_\_\_\_
9. Which of the following professionals is available by consultation to be a part of **pediatric-centered** survivorship care? (check all that apply)
- MD/DO (subspecialty: \_\_\_\_\_)
  - NP (subspecialty: \_\_\_\_\_)
  - PA (subspecialty: \_\_\_\_\_)
  - RN (subspecialty: \_\_\_\_\_)
  - Nutritionist
  - Social Worker
  - Psychologist
  - Trainee (fellow/resident/medical student)
  - Other: \_\_\_\_\_
10. Which of the professionals checked in question 8 and 9 submit a bill for their services? (check all that apply)
- MD/DO
  - NP
  - PA
  - RN
  - Nutritionist
  - Social Worker
  - Psychologist
  - Other: \_\_\_\_\_
11. Does your program have a formal mechanism for tracking clinical information about survivors receiving **pediatric-centered** survivorship care (such as a database)?
- Yes
  - No
12. Does your program have designated personnel to support research needs related to **pediatric-age** survivors of childhood cancer, such as a clinical research assistant (CRA)?
- Yes
  - No

## SUPPORTING INFORMATION

**The following are general questions about survivors of childhood cancer that are now adults and their survivorship care.**

13. Through your program or elsewhere, is specialized survivorship care available to transfer adult survivors from the pediatric model of care to the adult model of care?
- Yes
  - No

If answer is b. No → #46, If answer is a. Yes → #14

14. If clinically indicated, may adult survivors receive life-long care through this program?
- Yes
  - No

If answer is b. No, → #15, If answer is a. Yes → #16

15. At what age does specialized survivorship care stop?
- 22-25 years
  - 26-30 years
  - 31-35 years
  - ≥ 36 years
  - ≥ 50 years

16. What is the discipline (specialty area) of the clinical provider(s) who delivers care to your adult survivors of childhood cancer?
- Pediatric oncology
  - Adult oncology
  - Pediatric and adult oncology
  - Internal medicine/family practice (primary care provider)
  - Pediatric oncology and internal medicine/family practice
  - Adult oncology and internal medicine/family practice
  - Adolescent medicine
  - Other: \_\_\_\_\_

17. Which of the following professionals make up the clinical team that is routinely present to deliver **adult-centered** (see definition above) survivorship care to your patients? (check all that apply)
- MD/DO
  - NP
  - PA
  - RN
  - Nutritionist
  - Social Worker
  - Psychologist

## SUPPORTING INFORMATION

- h. Other: \_\_\_\_\_
18. Which of the following professionals make up the clinical team that is available by consultation to be a part of **adult-centered** survivorship care to your patients? (check all that apply)
- a. MD/DO (subspecialty: \_\_\_\_\_)
  - b. NP (subspecialty: \_\_\_\_\_)
  - c. PA (subspecialty: \_\_\_\_\_)
  - d. RN (subspecialty: \_\_\_\_\_)
  - e. Nutritionist
  - f. Social Worker
  - g. Psychologist
  - h. Other: \_\_\_\_\_
19. Which of the professionals checked in questions 17 and 18 above submit a bill for their services? (check all that apply)
- a. MD/DO
  - b. NP
  - c. PA
  - d. RN
  - e. Nutritionist
  - f. Social Worker
  - g. Psychologist
  - h. Other: \_\_\_\_\_
20. What is the clinical setting where this **adult-centered** survivorship care is being delivered?
- a. Pediatric cancer setting
  - b. Adult cancer setting
  - c. Pediatric non-cancer setting
  - d. Adult non-cancer setting
  - e. Other: \_\_\_\_\_
21. Is there an identified provider, such as a patient navigator or a care coordinator, who coordinates/facilitates the transition?
- a. Yes
  - b. No
- If answer is b. No → #23, If answer is a. Yes, → #22
22. Who provides the financial support for this role?
- a. Institution
  - b. Grants
  - c. Philanthropy
  - d. Other: \_\_\_\_\_

## SUPPORTING INFORMATION

23. Do you feel that insurance or reimbursement issues inhibit/prevent the transition of your survivors to adult-centered survivorship care?
- Yes
  - No

**The following questions ask about policies and procedures surrounding the transition from pediatric to adult centered survivor-focused care.**

24. Do survivors and their families receiving pediatric-centered care hear about the concept of transitioning their survivorship care to an adult-centered program greater than 1 year prior to the actual transfer?
- Yes, always.
  - Yes, sometimes.
  - No
25. Who usually introduces patients to the concept of transitioning survivorship care to an adult-centered program? (Choose all that apply)
- Survivorship physician
  - Survivorship nurse practitioner
  - Survivorship social worker
  - Survivorship nurse coordinator
  - Survivorship psychologist
  - Non-survivorship team member
  - Never
  - Other: \_\_\_\_\_
26. At approximately what age are patients introduced to the idea of transitioning care to an adult-centered model?
- Before age 14
  - 14-15
  - 16-17
  - 18
  - 19-21
  - 22+
  - Other: \_\_\_\_\_
27. At what age does your institution typically transfer patients to an adult-centered model of survivorship care?
- Before age 16
  - 16-17
  - 18-21
  - 22-25
  - After age 25

## SUPPORTING INFORMATION

28. Does your institution formally assess whether survivors are ready for the transition to adult-centered survivorship care?

- a. Yes
- b. No

If answer is b. No, → #31, if answer is a. Yes go to #29

29. How is this transition readiness assessed (check all that apply)?

- a. A standardized scale
- b. An internally developed scale/questionnaire/checklist
- c. Using provider opinion
- d. Other: \_\_\_\_\_

If answer is a. A standardized scale → #30, for all other answers → #31

30. If a standardized scale is used, what is it called: \_\_\_\_\_  
and where was it developed: \_\_\_\_\_

31. Are patients given a care plan or medical summary that summarizes previous cancer treatments and outlines necessary surveillance **at any point in their survivorship care**?

- a. Yes
- b. No

If answer is a. Yes → #32, if answer is b. No, → #36

32. **During the transition process** are patients given a care plan or medical summary?

- a. Yes
- b. No

If a. Yes → #33, if b. No → #34

33. **During the transition process**, when is the care plan or medical summary provided to the patient? (Choose all that apply)

- a. During pediatric-centered survivorship care
- b. At transfer from pediatric to adult survivorship care
- c. During adult-centered survivorship care

34. What type of document is the care plan (both content and format)? (Check all that apply)

- a. A medical summary with diagnoses and treatment received
- b. A plan of care for screening tests needed
- c. A paper document
- d. Part of the electronic medical record
- e. A transportable electronic document
- f. Other: \_\_\_\_\_

35. Who prepares the care plan?

## SUPPORTING INFORMATION

- a. Physician
- b. Nurse practitioner
- c. Nurse
- d. Other: \_\_\_\_\_

36. Does the patient get education about their disease, previous treatments and follow-up care **during or around the transfer to adult-centered care?**

- a. Yes
- b. No

If the answer is a. Yes → #37, if the answer is b. No → #39

37. How is the education delivered **during or around the transition to adult-centered care** (check all that apply)?

- a. Discussion during clinic time
- b. Educational handouts from COG
- c. Educational handouts developed by the institution
- d. Use of electronic resources (websites, etc)
- e. A formal survivorship course/curriculum
- f. Other: \_\_\_\_\_

38. Who provides education to the patient? (Check all that apply)

- a. A physician
- b. A nurse practitioner
- c. A nurse (educator, navigator, researcher)
- d. A social worker
- e. A psychologist
- f. Other: \_\_\_\_\_

39. Is insurance counseling provided to the survivor **during or around the transition to adult-centered care?**

- a. Yes
- b. No

If answer is a. Yes → #40, if answer is b. No → #41

40. Who delivers this insurance counseling to the survivor? (Check all that apply)

- a. A physician
- b. A nurse practitioner
- c. A nurse (educator, navigator, researcher)
- d. A social worker
- e. A psychologist
- f. Other: \_\_\_\_\_

41. Is vocational counseling provided to the survivor **during or around the transition to adult-centered care?**



## SUPPORTING INFORMATION

- a. Yes
- b. No

If answer is a. Yes, → #42, if answer is b. No → #43

42. Who delivers vocational counseling to the survivor? (Check all that apply)

- a. A physician
- b. A nurse practitioner
- c. A nurse (educator, navigator, researcher)
- d. A social worker
- e. A psychologist
- f. Other: \_\_\_\_\_

43. How is the accepting provider who delivers the adult-centered survivorship care notified of the transition? (check all that apply)

- a. By receipt of medical summary
- b. By e-mail
- c. By telephone
- d. In person via a joint visit
- e. The same provider sees survivor in both pediatric- and adult-centered settings
- f. They are not notified
- g. Other: \_\_\_\_\_

44. Does your program have a database which is used to track clinical information about **adult-age** survivors of childhood cancer?

- a. Yes
- b. No

45. Does your program have designated personnel such as a clinical research assistant (CRA) to support research needs related to **adult-age** survivors of childhood cancer?

- a. Yes
- b. No

### **Go to Question 50**

46. Do you believe that specialized survivorship care should be available to survivors of childhood cancer who are now adults?

- a. Yes
- b. No
- c. I don't know

If answer is a. Yes or c. I don't know → #48, if answer is b. No → #47

47. What is the primary reason that you believe specialized survivorship care should **NOT** be available to survivors of childhood cancer who are now adults? \_\_\_\_\_ Go to #50

## SUPPORTING INFORMATION

48. Do you believe that specialized survivorship care for adult-age survivors of childhood cancer should be **adult-centered** (see above definition)?

- a. Yes
- b. No
- c. I don't know

If answer is a. Yes or c. I don't know → #50, if answer is b. No → #49

49. What is the primary reason that you believe specialized survivorship care for adult-age survivors of childhood should **NOT** be adult-centered? \_\_\_\_\_ Go to #50

50. At your institution, what barriers exist to the transition of survivorship care to adult models of care (check your **top 3** barriers)?

- a. Lack of available adult providers to partner with
- b. Available adult providers lack knowledge in childhood cancer survivorship
- c. Limitations due to survivor insurance coverage
- d. Survivors no longer come to appointments
- e. Survivors desire to continue pediatric-centered care
- f. Parent/caregiver desires to continue pediatric-centered care
- g. Pediatric survivorship provider not willing to “let go” of survivor
- h. Survivors not ready for adult-centered care from a medical standpoint
- i. Survivors not ready for adult-centered care from a psychosocial standpoint
- j. Lack of the necessary adult subspecialty providers
- k. Adult models of care cannot accommodate influx of new patients
- l. Other: \_\_\_\_\_

51. Please let us know below if there is anything else you would like to share regarding transition of survivorship care to adult-center models of care?