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4 **A Qualitative Study: Transition and Aftercare for Survivors of Pediatric Cancer**
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6 **Across a Canadian Province**
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Abstract

Background: Childhood cancer survivors (CCS) face increased risks during the period when they leave pediatric-centres and transition into adult-focused aftercare.

We examine CCS's experiences entering adult-focused aftercare across an entire Canadian province, Newfoundland and Labrador (NL), to better understand current transition practices and identify opportunities for improving care.

Methods: We used a qualitative study design, based on semi-structured interviews of health care providers (HCP) and CCS in NL. HCP and CCS who recently transitioned out of pediatric care were identified and recruited using purposive sampling. Data was analyzed using both qualitative description and thematic analysis.

Results: Five CCS, five adult or pediatric oncologists, three allied health professionals, and one family physician were interviewed. No structured transition process for CCS was identified in the province. All CCS reported receiving aftercare through a children's oncology program, while only two reported receiving any form of aftercare in an adult setting. The barriers to improved transition identified were added challenges for survivors in rural areas, changes in the services available in adult-focused aftercare, challenges navigating the adult system and lack of education on transition and aftercare.

Interpretation: We found that there was little preparation and disruptions in aftercare related to CCS's transition into adult care. Programs serving CCS should aim to make these transitions more standardized and better supported, e.g., through the development of context appropriate educational resources.

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Keywords: Cancer survivorship; childhood cancer; aftercare; transitions

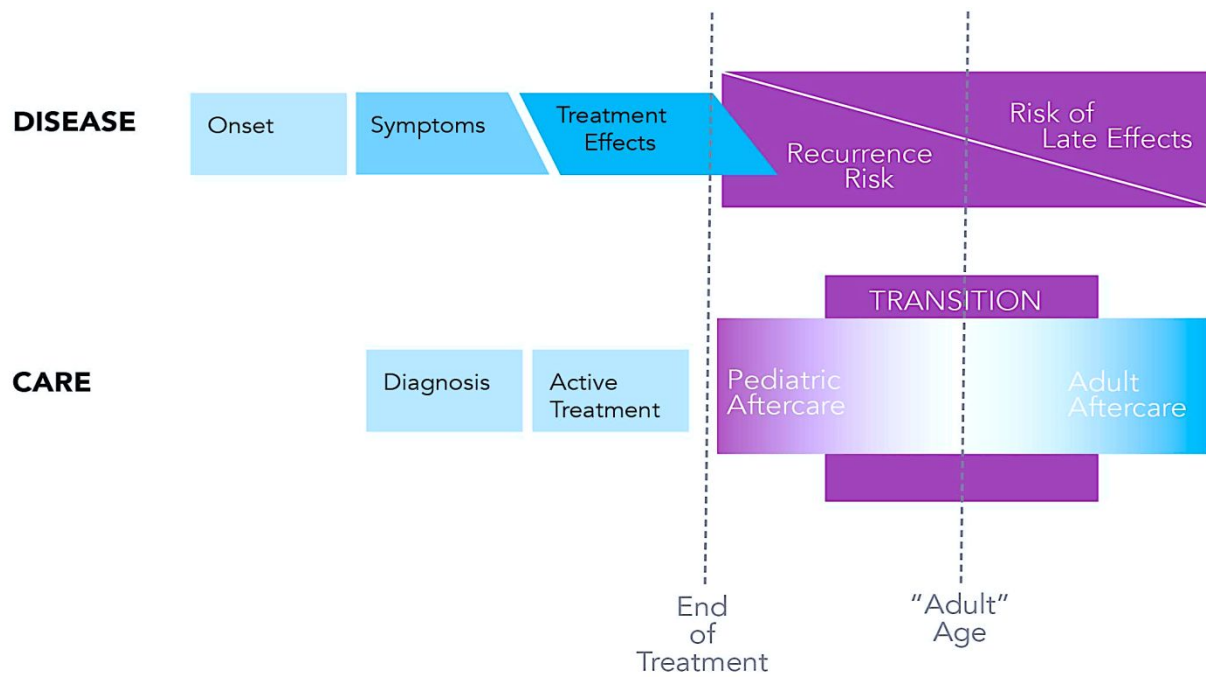
Confidential

1 Introduction

Advances in the treatment of childhood cancer have led to dramatic increases in the number of patients who survive their cancer and live well into adulthood [1-5]. Yet approximately two thirds of these CCS will be negatively impacted by their past cancer or from late effects from its treatment [6, 7]. Because of these elevated health risks, it is recommended that CCS be followed throughout their lives by appropriately trained health care provider (HCP) [6, 8-10]. This period of surveillance care is called follow-up care or aftercare. In *Figure 1*, we present a model that illustrates the typical disease-treatment progression for a CCS to highlight the place for transition and aftercare. After the onset of cancer and its symptoms, the cancer is diagnosed and treated. After treatment ends and the patient has no active cancer, there remains a life-long risk of cancer recurrence and negative impacts from receiving cancer treatment. Aftercare, which is the follow-up care received after active disease treatment ends, is dedicated to monitoring and managing these possible late effects. After treatment and aftercare in pediatric care settings, many CCS will transition and continue their aftercare in an adult-focused health care setting [11]. A key point for ensuring the continuance of aftercare is when CCS become adults and they usually leave pediatric programs and transition into the adult-focused health care system.

Despite clear health benefits, there are many challenges to maintaining optimal patient care during this transition into adult care [12-14]. While it is recognized that the transition into adult care is a critical period for CCS, we found few rigorous, first hand detailed accounts of how this transition occurs and barriers to transition during a recent systematic review of aftercare programs [5, 15]. Similarly, there were a limited number of interventions evaluated that were focused on supporting the transition of CCS, especially for interventions not limited to a single

24 aftercare program [12, 16, 17]. In this article, we present an in depth examination of current
 25 transition practices across an entire Canadian province, Newfoundland and Labrador (NL), to
 26 better understand current processes and identify opportunities for improving care.



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30 *Figure 1 Disease - Treatment Progression*

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32 **Methods**

33 *Study Design*

34 We used a qualitative research design based on key informant interviews and following the
 35 *Consolidated criteria for reporting qualitative research (COREQ)* [18].

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3 37 *Study Setting*
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6 38 We focused on NL for several reasons. It covers a large geographic region with many rural and
7
8 39 remote communities. NL only has one pediatric cancer program, located in its capital city,
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10 40 which treats patients from across the province. The pediatric oncology program at the Janeway
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12 41 Children's Health and Rehabilitation Centre (often referred to as the Janeway) manages between
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14 42 12 to 18 new pediatric cancer cases per year. Given the small size of the program, its HCP often
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16 43 develop lasting relationships with their patients and the program has high rates of retention
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18 44 within its pediatric aftercare program. Still it is unclear how and to whom survivors' transition
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20 45 once they entered the adult-focused health care system across the province. Following the World
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22 46 Health Organization (WHO) strategy for improving patient care, we aim to use this increased
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24 47 understanding of current transition processes to identify contextually appropriate interventions
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26 48 focused on improving transition and aftercare for these survivors [19].
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35 50 *Study Participants*
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38 51 Study participants included pediatric-focused HCP, adult-focused HCP and CCS who completed
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40 52 their care in the Janeway pediatric oncology program. HCP and CCS were identified and
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42 53 recruited using purposive sampling [20, 21]. Researchers recruited HCP who were directly
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44 54 involved in the care of CCS. HCP were identified by the Janeway pediatric oncology program
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46 55 and were recruited by e-mail. Emails were sent to 12 HCP. CCS who were 1) diagnosed with
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48 56 cancer before 18 years of age; 2) treated at the Janeway; 3) considered survivors of childhood
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50 57 cancer by their pediatric oncologist; and 4) currently over the age of 18 years were identified and
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52 58 invited through the Janeway Pediatric Oncology Program. Members of the survivors' circle of
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3 59 care identified 20 potential participants who fit these criteria. These CCS participants were
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5 60 contacted by mail and telephone and invited to participate. The interviewer had no prior
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7 61 relationship with interviewees.
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12 13 63 *Data Collection Procedures*

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16 64 A semi-structured interview guides reflecting the study objectives were developed for both CCS
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18 65 and HCP by the research team (Appendix A) [20]. Participants were given background
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20 66 information about the research project and primary objectives prior to the interviews. One
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22 67 female investigator (DR), a doctoral student with experience in conducting qualitative
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24 68 interviews, completed all the in-depth interviews between July 2017 and March 2019. Interviews
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26 69 were conducted in person or over the telephone depending on participants' availability and
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28 70 location. Interviews were between 15 and 60 minutes in length. The interviewer took fieldnotes
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30 71 throughout the interview. The interviews were audio recorded using the "Quicktime Player"
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32 72 application and were transcribed verbatim by a professional transcriptionist.
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39 40 41 74 *Data Analysis*

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44 75 We used qualitative descriptive and thematic analysis to evaluate the interviews [20, 22, 23].
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46 76 Qualitative descriptive is relevant as information is acquired directly from those experiencing the
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48 77 phenomenon of transition [24]. For the identification of barriers, we used a thematic analysis
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50 78 approach. Thematic analysis provided a structured method for identifying, organizing,
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52 79 describing and reporting themes [22, 25]. Thematic analysis allowed for the researchers to
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54 80 search for patterns in the data. Additionally, this analysis allowed the researchers to map
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3 81 important themes from the interviews. Data was initially coded by one member of the research
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5 82 team (DR). Coding was then reviewed and confirmed through discussions with the other authors
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7 83 (RC and PM). Any disagreements in coding were discussed with the research team until
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9 84 resolved. Following the initial coding, specific trends and reoccurring themes were identified.
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11 85 After completion of each interview, we compared and contrasted emergent themes and
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13 86 descriptions to ensure that the main ideas, interpretations and perspectives were captured from
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15 87 the participants' interviews [20]. Researchers conducted analysis alongside data collection until
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17 88 the point of saturation was obtained and after a period when all invited participants had an
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19 89 opportunity to participate. Participants did not provide feedback on the findings.
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30 91 *Ethics Approval*

31 92 Ethics approval for the project was granted by the Newfoundland and Labrador Health Research
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33 93 Ethics Authority[26].
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39 95 **Results**

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41 96 We interviewed five CCS, five adult or pediatric oncologists, three allied health professionals
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43 97 (dietitian, physiotherapist and social worker), and one family physician. *Table 1* breaks down
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45 98 information related to the CCS interviewed. In order to maintain participant confidentiality, the
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47 99 demographic information of participants was not broken down further. Interviews were held
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51 100 with 9 of the 12HCP who were invited to participate. Of the 20 invitation letters sent to CCS, 5
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53 101 CCS participated in an interview.
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103 *Table 1 Characteristics of CCS*

CCS Number	Urban/ Rural	Age at Diagnosis	Diagnosis	Treatment	Janeway Aftercare (age completed)	Adult Aftercare
CCS 1	Urban	10 years	Unknown	Chemotherapy and radiation therapy	Yes (21)	None
CCS 2	Urban	6 months	Wilm's Tumor	Chemotherapy, radiation therapy and kidney removal	Yes (18)	Follow up with cardiologist every three years; no other aftercare
CCS 3	Rural	18 months	Leukemia	Chemotherapy	Yes (19)	None
CCS 4	Rural	3 years	Acute Lymphoblastic Leukemia	Chemotherapy	Yes (18)	Yes (general physician at Adult Hospital)
CCS 5	Urban	8 years	Acute Lymphoblastic Leukemia	Chemotherapy (other treatments but unable to recall the specifics)	Yes (22)	None

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106 All the CCS interviewed received pediatric aftercare until 18 years of age or older. Only two
 107 reported receiving aftercare after leaving pediatrics. One CCS was unsure of their specific cancer
 108 diagnosis while another struggled to recall all aspects of their treatment, which are key pieces of
 109 information survivors should know in order to help direct their future aftercare.

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111 *The Process of Transition for CCS*

112 The Janeway Pediatric oncology program consists of three full-time pediatric oncologists. They
 113 jointly care for all pediatric patients with a cancer diagnosis in NL. Other allied HCP also
 114 support CCS, including a physiotherapist, a dietitian, psychologists and social workers. We
 115 identified three different points at which transitions to adult care usually occur at the Janeway: 1)

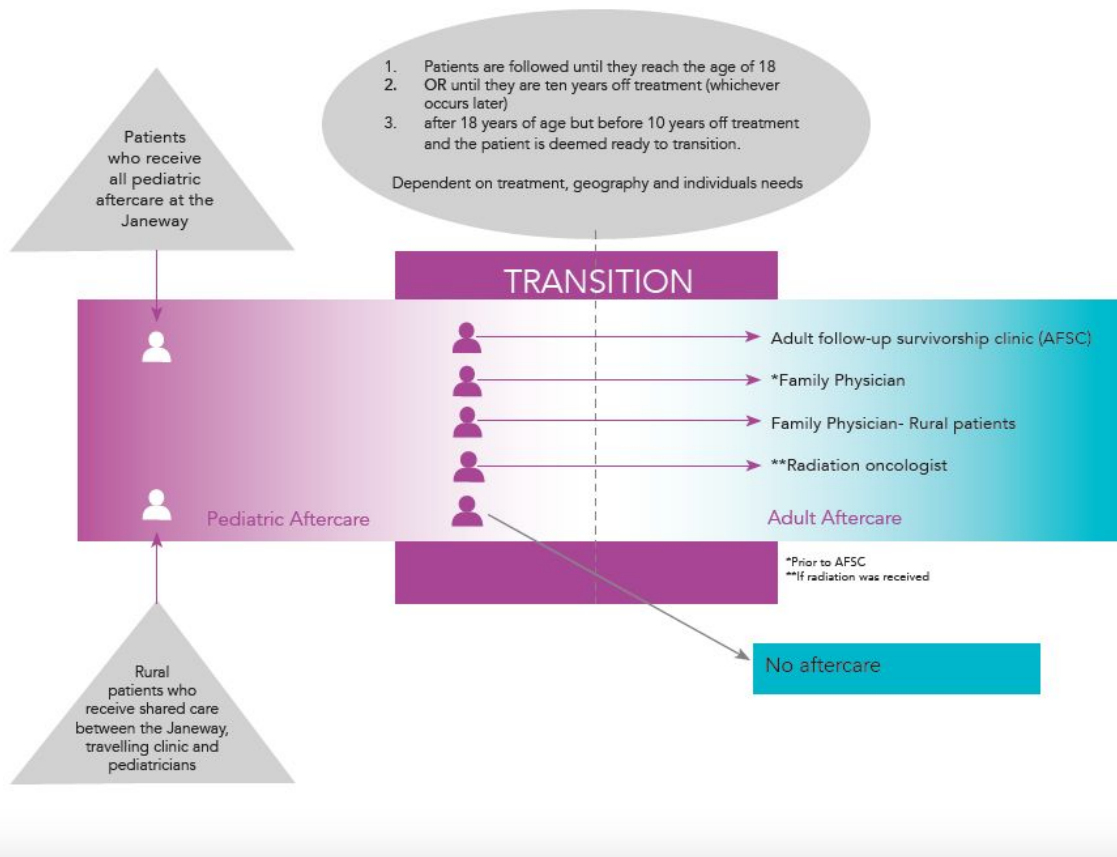
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3 116 survivors are followed until they reach the age of 18; 2) until they are ten years off treatment (if
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5 117 later than the first condition); or 3) after 18 years of age but before 10 years off treatment and the
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7 118 survivor is deemed ready to transition by the pediatric oncologist. In all cases, decisions about
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9 119 transition of survivors are made in discussion with the survivor, their families and other HCPs.
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11 120 The transition and aftercare trajectory depend on the CCS type of cancer, treatments received
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13 121 and their geographic location. HCP stressed that depending on cancer diagnosis and treatment,
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15 122 CCS would receive specific aftercare. For example, CCS #2 received specific aftercare related
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17 123 to potential cardiac late effects; however, no other CCS interviewed reported other special
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19 124 aftercare arrangements.
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27 126 Currently, there is no structured transition program in NL or regular advanced education about
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29 127 transition into adult aftercare. During a survivor's last clinic visit at the Janeway, the pediatric
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31 128 oncologist would usually review a summary of their care with them, including their original
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33 129 diagnosis, treatments received, risks of late effects associated with treatment and follow-up care
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35 130 needed (e.g., special screening). Similarly, there are no formal transition procedures that allied
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37 131 health providers follow. Depending on their needs, survivors may or may not be followed by
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39 132 allied health providers into adult aftercare.
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46 134 There are several possible destinations for CCS after they transition from the Janeway (Figure 2).
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48 135 A local family physician recently started an adult follow-up survivorship clinic (AFSC). This
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50 136 AFSC has been underway for approximately 3 years, with an estimated four or five CCS
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52 137 transitioning to the clinic annually. CCS #4 reported receiving aftercare through the AFSC. If a
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54 138 patient has received radiation as part of their treatment, the radiation oncologist also follows the
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139 patient alongside the AFSC. Pediatric oncologists reported that survivors who transitioned prior
 140 to the inception of the AFSC were often referred back to their family physician. The AFSC
 141 program is in the provincial capital city, therefore, CCS from rural communities are still usually
 142 transferred back to their family physician for aftercare. It is possible that survivors' aftercare
 143 arrangements may change over time depending on their location and other circumstances.

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146 *Figure 1 Current Transition Process for CCS in NL*

147 *Barriers to Improving the Transition and Aftercare*

148 We identified the following barriers to improving CCS' aftercare experience: challenges for rural
 149 survivors, changes in availability of services after transition, challenges with navigating the adult

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3 150 system and lack of education surrounding transitions. *Table 2* highlights quotes of HCP and
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5 151 CCS as they relate to each theme.
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11 153 *Challenges for Rural Survivors*
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14 154 HCP and rural CCS reported considerable differences in how survivors receive care. With no
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16 155 pediatric care hospital outside the capital city, families reported traveling considerable distances
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18 156 to receive care or they receive care through travelling clinics. Survivors without a family
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20 157 physician in their rural community often rely on pediatric travelling clinics for all their primary
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22 158 care, making transition a further challenge. After transitioning out of pediatrics, participants felt
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24 159 there were a limited number of family physicians available to take over their care. Others
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26 160 reported that family doctors may not have the same understanding of cancer care as the dedicated
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28 161 AFSC. Survivors in rural areas also face inequities of access to allied health services and mental
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30 162 health support. One interviewee said “a new way of doing business” needs to be considered for
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32 163 how aftercare is provided in rural areas.
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41 165 *Changes in Availability of Services After Transition*
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44 166 Pediatric oncologists discussed the importance of allied health support received by CCS. Once
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46 167 survivors go back to their family doctor or to the AFSC, these supports are viewed as less
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48 168 accessible. While the adult health care system ideally has all the same services, the onus is on
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50 169 the patient to arrange for care and manage appointments. CCS reported having trouble accessing
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52 170 allied health professionals in the adult system, with long wait times to access services if they are
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54 171 even available. Additionally, allied health services for adults are not always accessible under
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3 172 public-funded health coverage programs. Without private insurance, these services can be costly
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5 173 and not all survivors are able to pay out-of-pocket. After leaving the pediatric care setting, CCS
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7 174 commonly discussed a loss of access to psychological supports. One HCP discussed the need for
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9 175 a multidisciplinary cancer aftercare program for adult CCS to help mitigate the loss of these
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18 178 *Challenges with Navigating the Adult System*

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21 179 After transitioning to adult care, CCS are expected to have a certain level of autonomy and it is
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23 180 up to the patient to identify their needs and arrange for appointments. From our sample, those
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25 181 who do not have stable, continuous housing; who do not have a regular family physician; or who
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27 182 still rely on their parents to organize their care often have challenges navigating the adult
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29 183 healthcare system. In the adult system, some tools (i.e., patient navigators) are provided to help
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31 184 navigate the system for active cancer patients, although the CCS we spoke with were unaware of
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33 185 these resources. CCS felt they left pediatric aftercare not knowing when they would be
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35 186 contacted by their new provider to receive aftercare from the adult system. Despite the potential
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37 187 role for navigators in the adult system, previous pediatric providers are commonly still the first
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39 188 point of contact because CCS do not know who else to communicate with when issues arise.
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48 190 *Lack of Education Surrounding Transition*

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51 191 Participants said that there is currently no formal preparation for CCS transitioning in NL. The
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53 192 pediatric oncologist does provide a medical summary to the physician accepting the patient and
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55 193 provides the patient additional information including screening appointments (dependent on
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3 194 cancer diagnosis and treatment) and any other pertinent information related to CCS diagnosis or
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5 195 treatment. This is usually done by the pediatric oncologist who conducts the last clinic visit.
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8 196 HCP and CCS discussed the need for a site visit to where the CCS is transitioning, an
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10 197 introduction to the new HCP, and more information on how to manage their future healthcare
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12 198 needs. Survivors reported experiencing a general lack of communication between both the
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14 199 pediatric and adult healthcare systems. It was suggested that education should begin earlier in
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16 200 the pediatric care setting. A more formalized approach would begin before a patient's last visit
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18 201 and include educating the CCS about their past cancer, developing plans to help navigate the
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20 202 healthcare system and meeting with the receiving adult HCP while still in pediatric care settings.
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22
23 203 This approach provides the opportunity to "create a bridge to a new context." HCP recognize the
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25 204 need to prioritize transition; however, there is a tendency for it to get lost in amongst other health
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207 Table 2 Key Theme and Supporting Quotes from HCP and CCS

Key Theme	Identification Code	HCP Quote	Identification Code	CCS Quote
Challenges for Rural Survivors	HCP2	<i>I find that on the West Coast [of NL], or outside of St. John's, with the patients that we see in our Traveling Clinics, because, the family physicians are so in flux in rural communities that most of these patients don't have a family physician and often, we're the only people that they see.</i>	CCS4	<i>It's a big difference [being in a rural community] because it's a 12-hour drive [to the Janeway Hospital], so to come in here every year to get the check up, it was a big deal.</i>
Changes in Availability of Services After Transition	HCP6	<i>I wouldn't say 'loss of services'... I think that, maybe there are some services that are not as emphasized on the adult side... On the pediatric side, there's a little bit more emphasis on the sort of social work part, school, integration those sorts of things. That all of those resources are available on the adult side, I just don't think that there's as much emphasis.</i>	CCS2	<i>I feel like I'm missing out on a lot of resources that could be beneficial to me and even when I was in the pediatric care, they were talking about regular screening and things like that, but it was just general conversation.</i>
Challenges with Navigating the Adult System	HCP2	<i>I think the biggest problem for patients that are not connected to any place or person. They're not connected to a family doctor because they are moving around the province for school, or the country for school or jobs and so, they're not, they're not grounded anywhere to maintain those connections. I think if you polled most young adults, they would have no idea [how to navigate the health care system].</i>	CCS3	<i>[Be]cause I feel like it was more of a miscommunication in care where maybe one person thought it was being taken care of... or they thought it was somebody else's job, but I wasn't ever followed up. I was told I would have been and have something in place to transition children from the Janeway to the Health Science, or whatever the hospital that they're seen at.</i>
Lack of Education Surrounding Transitions.	HCP1	<i>We don't do a lot of [formal preparation] like I said, we don't have any formal preparation... we do occasionally mention to people, if they're coming up on ten years off treatment or if they're coming up on 18 years old, we might mention to them... "next time we see you, we'll have to talk about transition to the adult system cause that's coming up."</i>	CCS2	<i>The barriers I feel were like miscommunication and care. Maybe it's just me and I got... slipped into the cracks in the system or whatever, but, that's definitely a barrier and I think to enable their care, they could have a better transitioning system.</i>

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209 **Interpretation**

210 In this study, we examined the process of transition from pediatric to adult care for CCS and
211 identified barriers to transition for CCS in one Canadian province for both its urban and rural
212 populations. We found the process for transitioning had insufficient structure and lacked
213 dedicated supports. In fact, the transition occurred as a discrete event rather than “the
214 purposeful, planned movement of adolescents and young adults with chronic physical and
215 medical conditions from child-centred to adult- oriented health care systems” that transition
216 should aim to be [27-29]. Only two CCS reported any form of adult aftercare. From these
217 participants alone, there is a gap in care that is essential to the well-being of these survivors.
218 Other barriers to transition identified included challenges for rural survivors, changes in
219 availability of services after transition, challenges with navigating the adult system and lack of
220 education surrounding transitions.

221 Our findings reflect a situation commonly faced by CCS. A cross-Canada survey found that 88%
222 of pediatric oncology programs reported following LTFU guidelines but only 35% had access to
223 a formal transition program[30]. Moreover, we found that CCS in rural communities face
224 additional challenges accessing aftercare. Such inequities in rural healthcare are prevalent
225 throughout many jurisdictions [31]. Access to health care facilities influences patient outcomes
226 [32, 33]. It is also the case that direct and indirect costs associated with travel amplify the
227 challenges for rural CCS [34]. Other studies have compared CCS in rural communities with
228 gender-matched peers and report poorer social competence, greater behavioral issues and weaker
229 overall school performance in rural CCS [35] [36]. Strategies that help reduce costs and time of
230 travel - such a tele-health, travelling clinics and other creative services - should be further
231 investigated to better serve CCS living in rural areas. Education for HCP and CCS is another

1
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3 232 key feature of successful aftercare. Components of education during CCS transition that have
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5 233 been identified as necessary include knowledge about one's disease, disease treatment, future
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7 234 health risk, self-management skills and coordination of care [17, 37]. Our research highlights
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9 235 that CCS may not have sufficient knowledge to maximize engagement with the healthcare
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11 236 system during transition. Our findings are consistent with the Childhood Cancer Survivorship
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13 237 Study (CCSS), which found that only 72% of CCS could correctly recall their diagnosis and only
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15 238 35% were able to report awareness of any health risks [2]. Ginsberg et al. reported similar
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17 239 findings whereby CCS were unable to report basic information regarding their health [38]. Some
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19 240 CCS lack the skills required to advocate for themselves as they progress into adult care [39, 40].
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22 241 Participants in our study are supportive of an educational intervention to improve the transition
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24 242 from pediatric to adult care for CCS. One direction of our future work will be on the
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26 243 development and evaluation of an educational intervention relevant to our study population.
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29 244 While our study provides a solid base to make recommendations for improving care, there are
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31 245 some limitations. This qualitative research only studied the transition experience of survivors in
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33 246 one Canadian province. While similar barriers to improved transition care likely occur in other
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35 247 jurisdictions, caution should be taken when applying these findings to other populations. Despite
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37 248 best efforts and numerous methods of recruitment, we hoped that more CCS would have
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39 249 participated and given their perspectives. It is not known how those who participated in the
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41 250 study differ in their experience from those CCS who did not.
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51 251
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53 252 *Conclusion*

54 253 HCP and CCS delivered a clear picture of the process by which transition into the adult system
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56 254 occur in NL and identified the barriers associated with transition. Key stakeholders recognize

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3 255 the need to improve these gaps and offered tangible ideas to support future interventions targeted
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5 256 at transition. Our results show that despite adherence to clinical guidelines for aftercare and high
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8 257 levels of satisfaction from CCS, a clear, more structured process for transition for CCS is likely
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10 258 needed. Our research also highlights the compounded challenges for CCS in rural communities.
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12 259 CCS and HCP in our study share a common goal to holistically improve the transition of CCS
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14 260 from pediatric to adult care. By following the methodical WHO framework, we hope that the
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17 261 better understanding of transition practices presented here will support the development of
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19 262 interventions which can more adequately prepare CCS during this vulnerable period.
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4 **264 Declarations**

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8 265 *Ethics approval and consent to participate:* Ethics approval was granted by the Newfoundland
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10 266 and Labrador Health Research Ethics Authority.

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13 267 *Consent for publication:* Not applicable

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17 268 *Availability of data and materials:* The datasets generated and/or analysed during the current
18
19 269 study are not publicly available due to the fact that are confidential interviews with patients and
20
21 270 providers, but are available from the corresponding author on reasonable request.

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25 271 *Competing interests:* The authors have no conflicts of interest or funding to disclose

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27
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30 273 Applied Research (Canada)

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34 274 *Authors' contributions:* DR completed the interviews, assisted in the development of research
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36 275 design and analysis. RC and PM assisted in the development of the research design recruitment
37
38 276 of participants. All authors read and approved the final manuscript.

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Appendix A

Interview Guide for CCS and HCP

Pediatric Oncologist Interview Guide

1. Could you describe your role as a health care provider?
2. Could you describe the process by which survivors of childhood cancer usually transition from your program into adult care?
 - a. At what age do patients usually transfer into adult care?
 - b. To whom do you usually transfer patients?
3. How do you currently prepare your patients for the transition into adult care?
 - a. At what age do you start to prepare your patients?
4. What concerns/challenges do patients raise to you about their transition to adult care before they are transferred?
5. How do you think your current process for transferring patients from your clinic is working?
6. Are there added difficulties in transition for survivors in rural areas?
7. Our pediatric oncology program has a high retention rate for survivors. Why do you think the program been able to maintain such high retention rates?
8. What do you believe the goals of transition should be?
9. In your experience, do your patients experience changes in their availability to services due to their transition into adult care?
10. What suggestions do you have for improving the transferring of your patients into adult care?
11. What model of care/aftercare do patients currently experience?

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a. What do you think would work best here in Newfoundland?

b. If no structure:

i. Does there need to be a structured program in Newfoundland?

12. Given the competing ways to improve patient care, how would you rank improving the transition to adult care as a priority for your program?

13. Would you be interested in further training in this area? And if so, in what format?

14. Do you provide patients the tools/information to navigate the health care system as they age?

15. Is there anything else that you would like to add?

16. Do you have any documents related to transition that you could share?

Confidential

Nurses/Allied Health Professionals Interview Guide

1. Could you describe your role as a health care provider?
2. Could you describe the process by which survivors of childhood cancer usually transition from your program into adult care?
 - a. At what age do patients usually transfer into adult care?
 - b. To whom do you usually transfer patients?
3. How do you currently prepare your patients for the transition into adult care?
 - a. At what age do you start to prepare your patients?
 - b. Does your organization give guidance of how the transition process should occur?
4. What concerns/challenges do patients raise to you about their transition to adult care before they are transferred?
5. How do you think your current process for transitioning patients from your clinic is working?
6. Are there added difficulties in transition for survivors in rural areas?
7. The Janeway pediatric oncology program has a high retention rate for survivors. Why do you think the program been able to maintain such high retention rates?
8. What do you believe the goals of transition should be?
9. Are you aware of any concerns regarding patients transition to adult care?
 - a. Are you aware of any challenge's patients experience after transitioning?
 - b. What do you see as the enablers and barriers of a good transition?
 - c. In your experience, do your patients experience changes in their availability to services due to their transition into adult care?

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3 10. What suggestions do you have for improving the transferring of your patients into adult
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5 care?

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8 11. What model of care/aftercare do patients currently experience?

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10 a. What do you think would work best here in Newfoundland?

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12 b. If no structure:

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14 i. Does there need to be a structured program in Newfoundland?

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17 12. Given the competing ways to improve patient care, how would you rank improving the
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19 transition to adult care as a priority for your program?

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22 13. Do you feel you were adequately trained to best assist your patients as they reach the
23
24 point on transition?

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26 a. Would you be interested in further training in this area? And if so, in what
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28 format?

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31 14. Do you provide patients the tools/information to navigate the health care system as they
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33 age?

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35 15. Are there any resources or supports that you would like to see developed to better support
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37 either patients or providers?

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40 16. Is there anything else that you would like to add?

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42 *17. Do you have any documents related to transition that you could share?*
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Family Physicians Interview Guide

1. Could you describe your role as a health care provider?
 - a. What is your role as it relates to childhood cancer survivors?
 - b. Experience with childhood cancer survivors?
2. Could you describe the process by which survivors of childhood cancer usually transition into your program?
 - a. At what age do patients usually transfer into adult care?
3. Approximately how many survivors of childhood cancer do you currently have in your practice?
 - a. How many would you typically have transfer to your practice in a year?
4. At what age do patients usually transfer into your practice for the care of their cancer?
5. Does your organization give physicians guidance of how the transition process should occur?
6. The Janeway Oncology program has had high retention rates in their aftercare program. Why do you believe the pediatric oncology program has been able to maintain such high retention rates?
7. What do you believe the goals of transition should be?
8. What do you see as enablers and barriers of good transition?
9. Do you feel survivors of childhood cancer are usually prepared to make the transition when they do?
10. How well do you think the current model of transition working?

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3 11. How do you think the current process for transferring patients from your clinic is
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5 working?
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8 12. What concerns do patients raise to you about their transition to adult care?
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11 13. In your experience, what challenges do patients experience after transitioning?
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14 14. In your experience, do your patients experience changes in their availability to services
15 due to their transition into adult care?
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18 15. What model of care/aftercare do patients currently experience? (Provide background if
19 needed)
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 - 21 a. What do you think would work best here in Newfoundland?
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 - 23 b. If no structure:
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 - 25 ▪ Does there need to be a structured program in Newfoundland?
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29 16. What suggestions do you have for improving the transitioning of survivors of childhood
30 cancer into adult care in our province?
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33 17. Do you feel you were adequately trained to best assist your patients as they reach the
34 point on transition?
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37 18. Would you be interested in further training in this area? And if so, in what format?
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40 19. Do you provide patients the tool to navigate the health care system as they age?
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43 20. In your experience, do your patients experience difficulties with navigating the healthcare
44 system
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47 21. Is there anything else that you would like to add?
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50 22. Do you have any documents related to transition you could share?
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Childhood Cancer Survivors Interview Guide

1. Could you provide me with some details of your;
 - a. Cancer diagnosis
 - b. Treatment
2. When did you complete your treatment?
3. How old were you when you:
 - a. Finished pediatric care?
 - b. Transferred into adult care?
4. Could you describe what happened when you finished your care at the Janeway
 - a. Pediatric aftercare?
 - b. How long was care provided at the Janeway?
5. After your time at the Janeway, what did your care for your past cancer diagnosis look like?
6. Are you aware of any aftercare?
 - a. Are you aware of any guidelines for survivors?
7. Was there any conversation about a transition from the Janeway into adult care?
8. What do you believe the goals of transition should be?
9. How well is the current transition model meeting these goals?
10. What was the process by which you were transferred to an adult physician?
11. What did your pediatric care team do to prepare you for the transition into adult care?
12. Did you feel prepared to make the transition when you did?
13. Who is responsible for your long-term follow-up?

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- a. Who were you referred to for your adult aftercare?
14. Who are you currently seeing for any cancer related issues?
15. How do you feel about how you were transferred into adult care?
16. Do you have any concerns about your transition to adult care?
17. Did you experience changes in availability of services due to your transition into adult care?
- a. If so, how are you dealing with the loss of services?
18. What type of aftercare do you think would work best here at the HSC?
19. Where are you in your aftercare (explain, if needed)?
20. What is your understanding of the point of aftercare?
21. What do you see as enablers for a good transition?
- a. Barriers of good transition?
22. What suggestions do you have for improving the transition into adult care for survivors of childhood cancer?
23. How do you find navigating the healthcare system?
- a. Do you have any challenges?
- b. Has anyone helped you?
24. Is there anything else that you would like to add?

Adult Provider Interview Guide

1. Could you describe your role as a health care provider?
2. Could you describe the process by which survivors of childhood cancer usually transition from your program into adult care?
 - At what age do patients usually transfer into adult care?
 - To whom do you usually transfer patients?
3. Approximately how many survivors of childhood cancer transition into your practice?
4. At what age do patients usually transfer from your practice into adult care?
5. Does your organization give guidance of how the transition process should occur?
6. Why do you believe the pediatric oncology program has been able to maintain such high retention rates?
7. What do you believe the goals of transition should be?
8. How well is the current transition model meeting your goals and your patients' goals?
9. How do you feel survivors of childhood cancer are usually prepared to make the transition when they do?
10. What do you see as the enablers and barriers of a good transition?
11. How do you think your current process for transitioning patients into your clinic is working?
12. Are you aware of any challenge's patients experience after transitioning?
13. In your experience, do your patients experience changes in their availability to services due to their transition into adult care?

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- 3 14. What type of MOC/aftercare do you think would work best here at the HSC? (Provide
- 4 explanation if needed)
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- 8 15. What suggestions do you have for improving the transferring of your patients into adult
- 9 care?
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- 12 16. Do you complete any professional development and/or education on caring for adult
- 13 survivors of childhood cancer?
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- 17 17. What supports and/or resources are in place for adult providers to care for survivors of
- 18 childhood cancer?
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- 21 18. Do you feel you were adequately trained to help with the transition process?
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- 24 19. In your experience, do your patients experience difficulties with navigating the healthcare
- 25 system?
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- 28 20. Is there anything else that you would like to add?
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- 31 21. Do you have any documents related to transition you could share?
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