

Attitudes and practices of Canadian pediatric and adult cancer treatment centers regarding care of adolescent and young adult (AYA) patients

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Canadian AYA Task Force**

AYA Introduction

- Adolescents and young adults (AYAs) aged 15-29 years are a largely understudied population with regard to cancer.
- In 2005, nearly 2300 cancer cases (1.5% of all cases in Canada) and approximately 300 deaths due to cancer were reported in AYAs.

AYA Introduction

- Because cancer occurs relatively infrequently in AYAs, awareness of cancer in this age group is less than in older adults. AYAs often do not benefit from the specialized care available to children below 15 years of age.
- AYA cancers may have biologically distinct behaviour and respond differently to chemotherapy and other treatment for the same cancers in other age groups.

AYA Introduction

- AYAs are becoming recognized as a group with distinct needs. Their unique psychosocial needs are not often addressed in pediatric or adult oncology centres.
- Young adulthood is a stage of development involving many life-related changes, including decisions about employment, education, relationships, and family that can be severely impacted by a cancer diagnosis

AYA Introduction

- The small number of cancers in this age group does not appropriately reflect the personal and societal costs of cancer in this population, as reflected in the potential years of life lost.
- Cancers in AYAs may also be detected later in their course because young people sometimes delay seeking medical advice or they do not routinely have medical care during which cancer symptoms can be identified

AYA Introduction

- Adding to the challenge of providing appropriate health care to this population is the recognition of the needs of survivors of malignant diseases in childhood (0-14 years).
- It has been estimated that 1 in 640 of the population between the ages of 20 and 39 years is a childhood cancer survivor.
- Approximately a third of all such survivors will have one or more important adverse sequelae from the treatment for their disease

AYA Introduction

There is a manifest need to bridge the gap between the paediatric and adult health care systems to meet the requirement of specific care for the AYA patient with cancer and the AYA patient who is a survivor of cancer.

AYA Task Force

In response, a Canadian national task force of health care providers, survivors and other stakeholders has been formed to address issues facing AYA with cancer

Objectives AYA Task Force

- To document cancer care for AYA in Canada with respect to their referral, diagnosis, treatment and psycho-social support (Current state)
- To report on patterns and transition models of long-term follow-up of survivors of cancer in childhood or AYA. (Current state)

Objectives AYA Task Force

- To establish recommendations for the provision of health care to AYA with cancer, and to survivors of cancer as children or AYA, in order to improve their overall outcomes and health-related quality of life (Desired state)
- To develop communication between pediatric and adult health care providers and stakeholders to promote improvement in the health care provided to AYA with cancer and to survivors of cancer as children or AYA (Desired state)

Objectives AYA Task Force

- To ensure that the AYA recommendations are implementable within the Canadian health care environment, and to ensure sustainability of the efforts to improve the care of AYA with cancer
- To stimulate and support research related to cancer and its sequelae in AYA

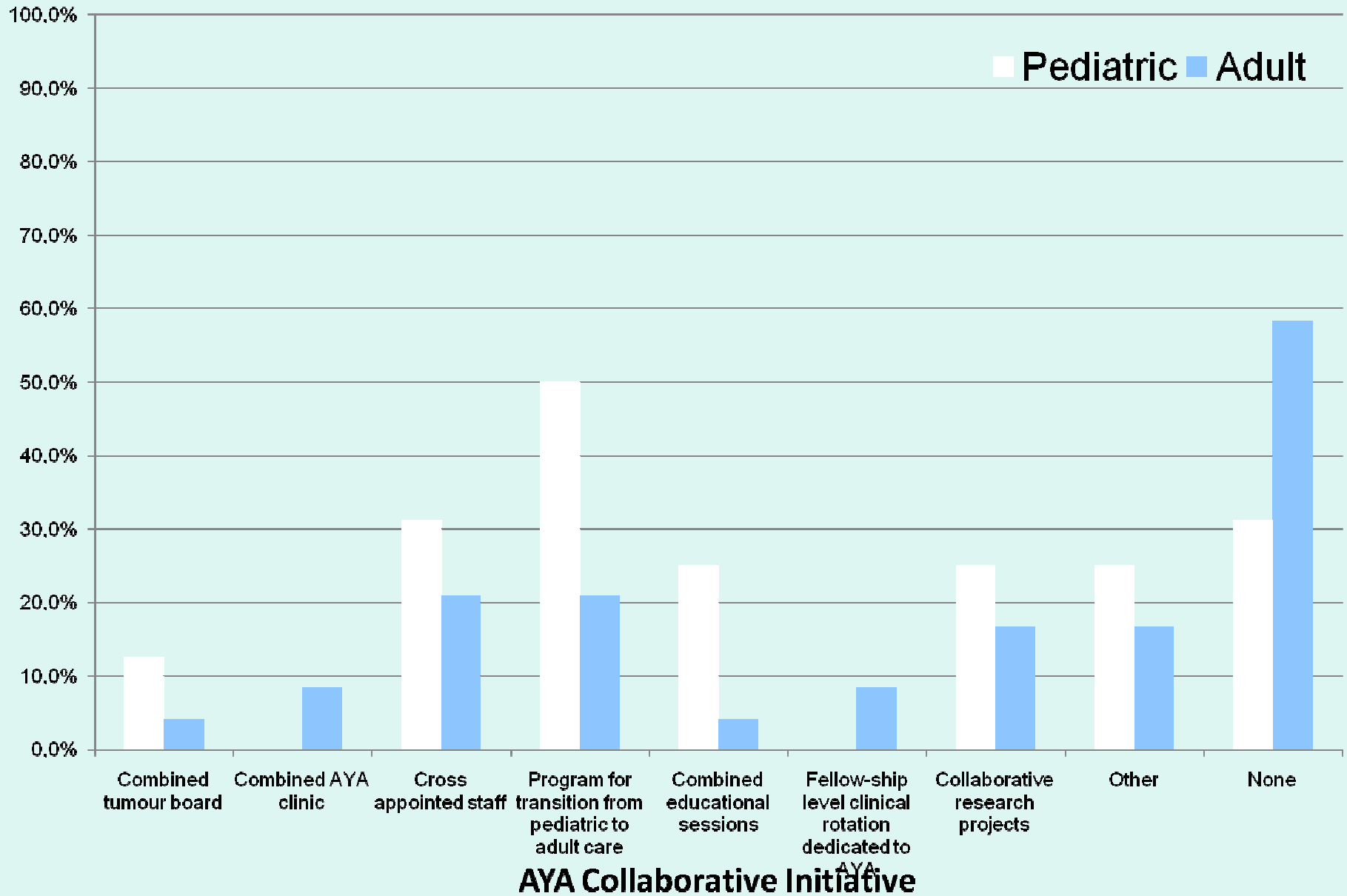
AYA Task Force Survey

- A questionnaire about services available to AYA cancer patients, and for follow-up care of survivors of cancer as children or AYA was developed by a working group of the AYA Task Force
- Questionnaires were mailed between April 15 and May 13, 2009 to:
 - C¹⁷ Council members, representing all pediatric cancer centers in Canada;
 - all cancer treatment institutions listed by the Canadian Association of Provincial Cancer Agencies (CAPCA).

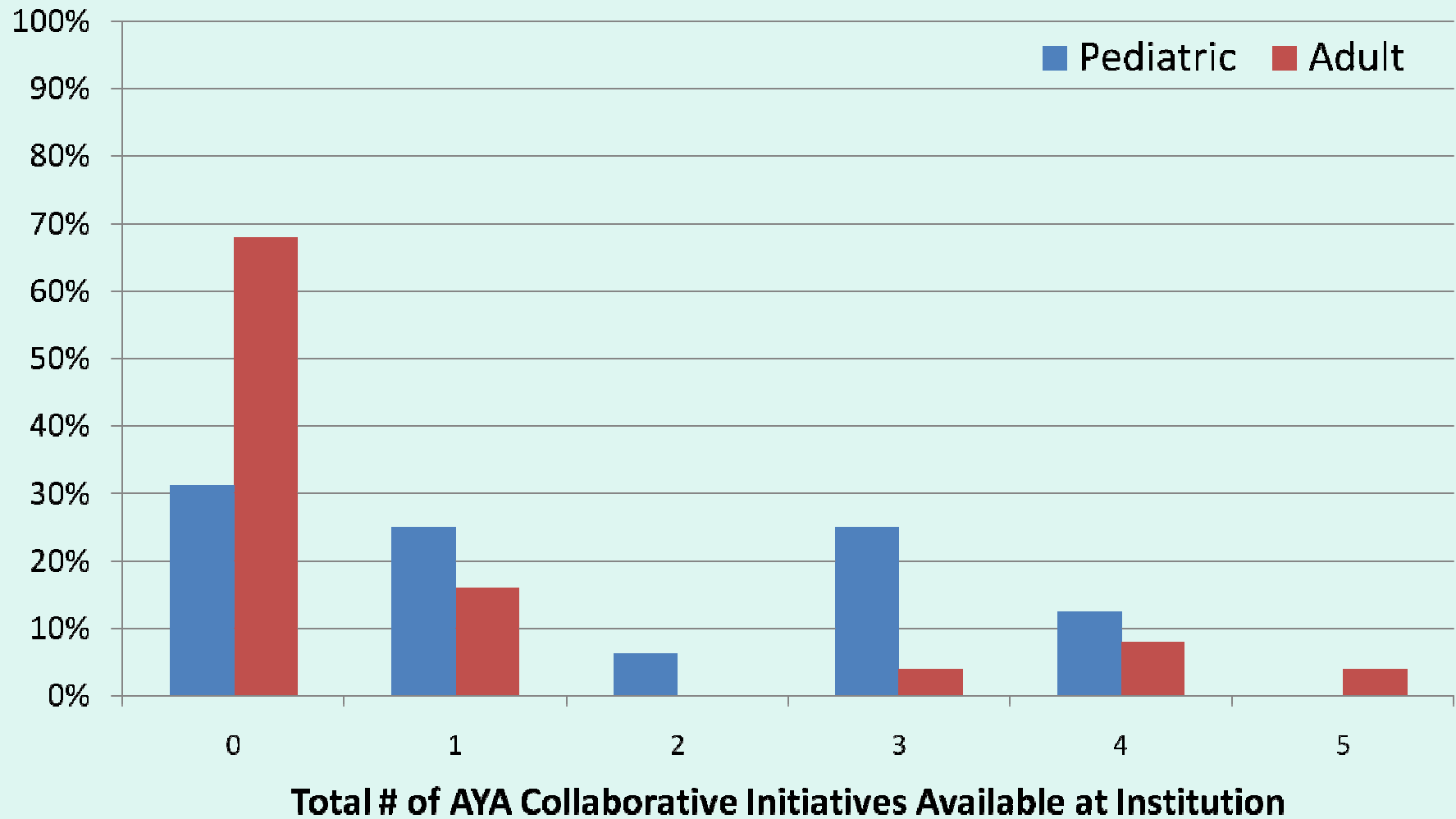
Table 1: Questionnaire Response Summary

	Returned	Sent	%
PEDIATRIC	16	16	100
ADULT	25	48	52
OVERALL	41	64	64

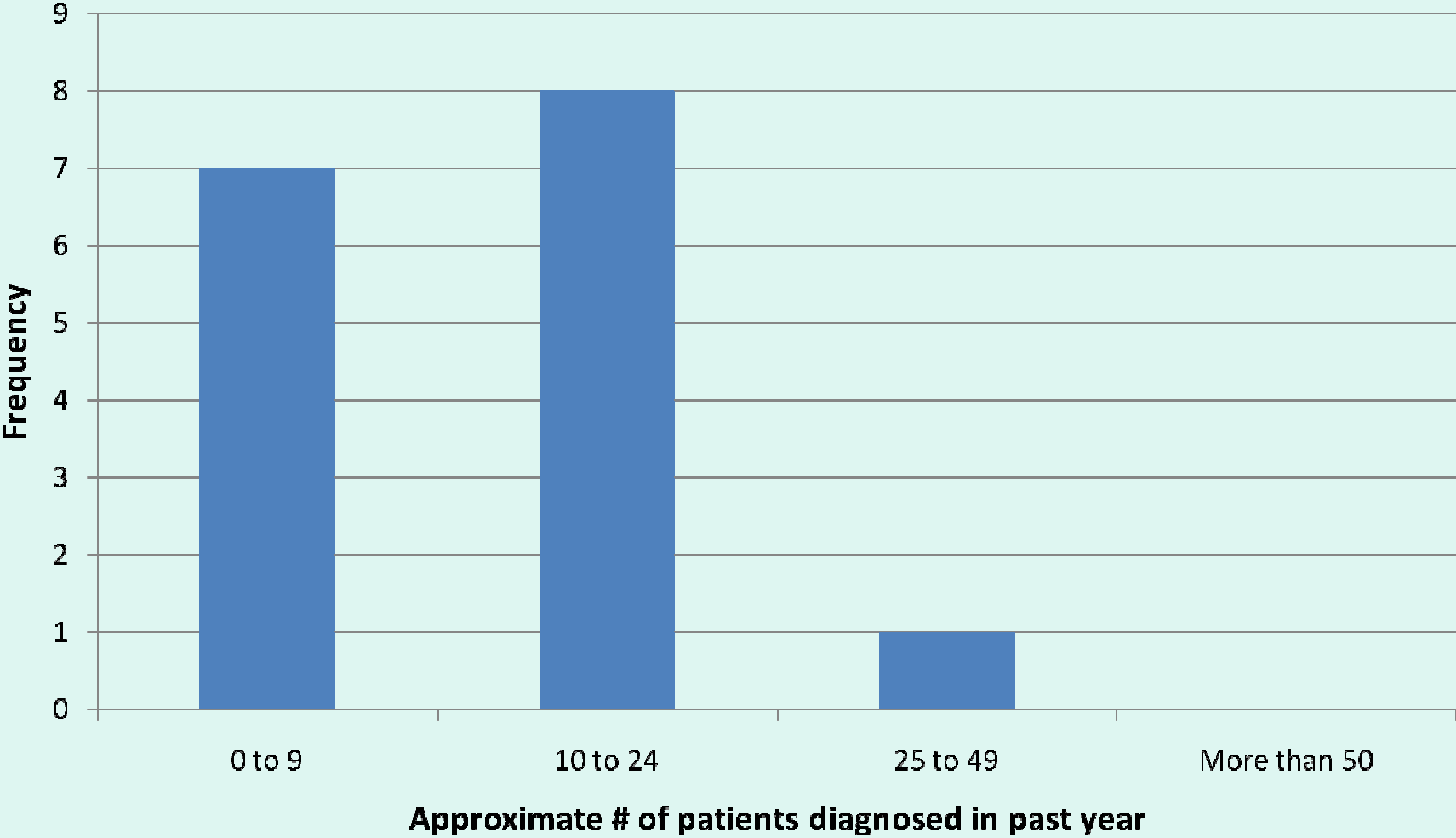
AYA Collaborative Initiatives (between peds & adult staff)



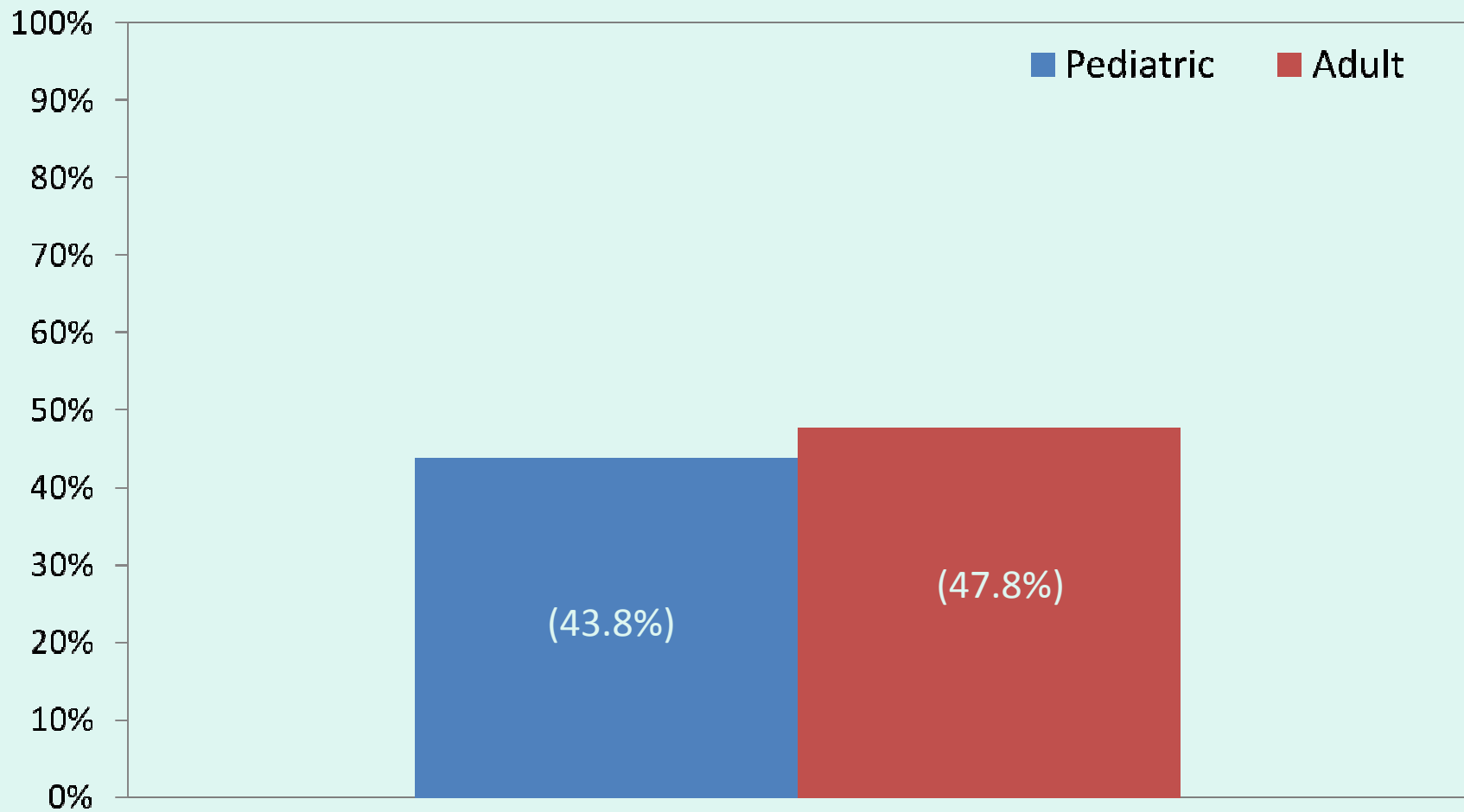
AYA Collaborative Initiatives (cont'd)



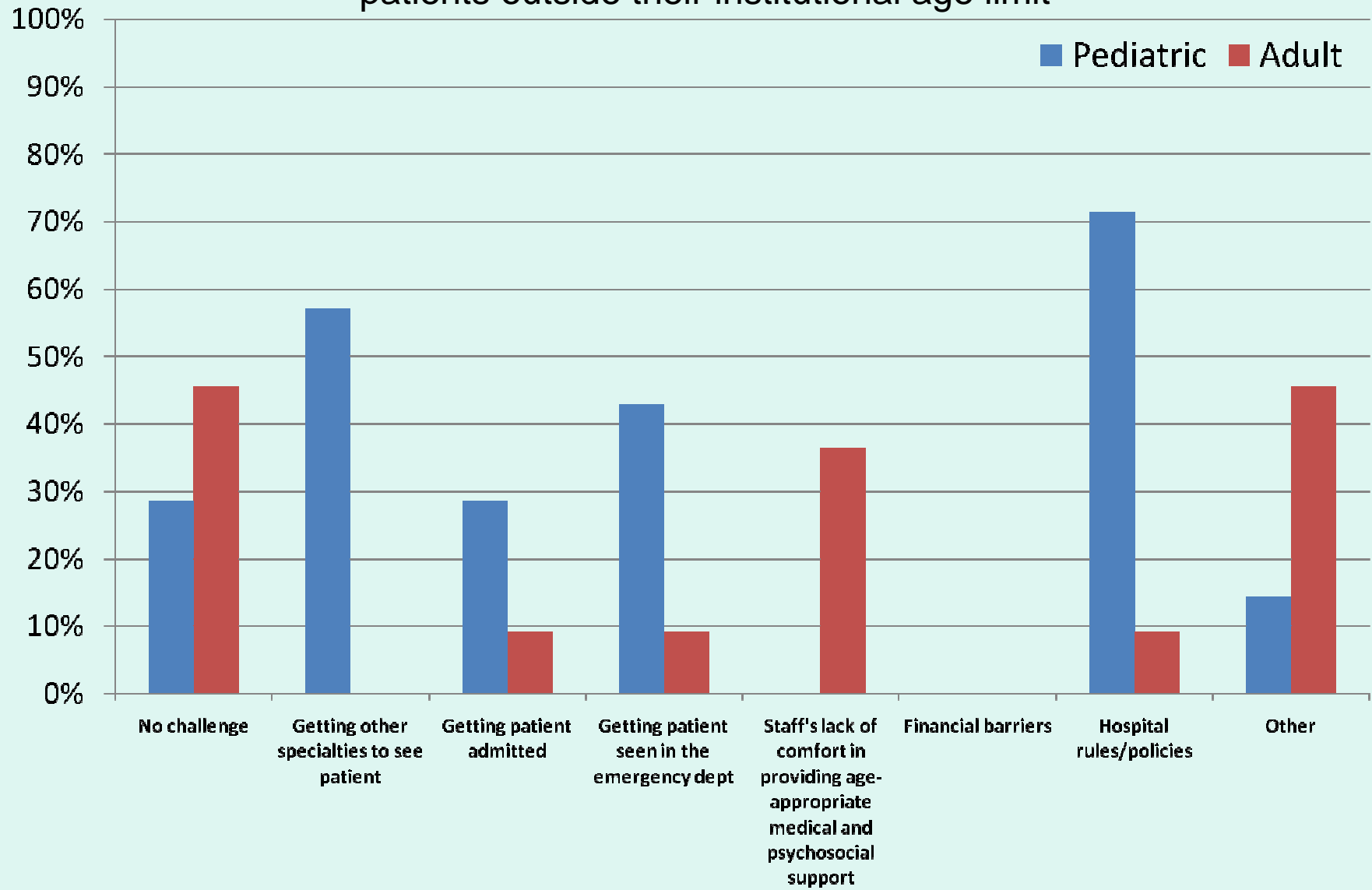
Frequency distribution by number of new cancer patients aged 15+ who were diagnosed within each pediatric institution



% of institutions starting treatment for newly diagnosed patients outside their age limit

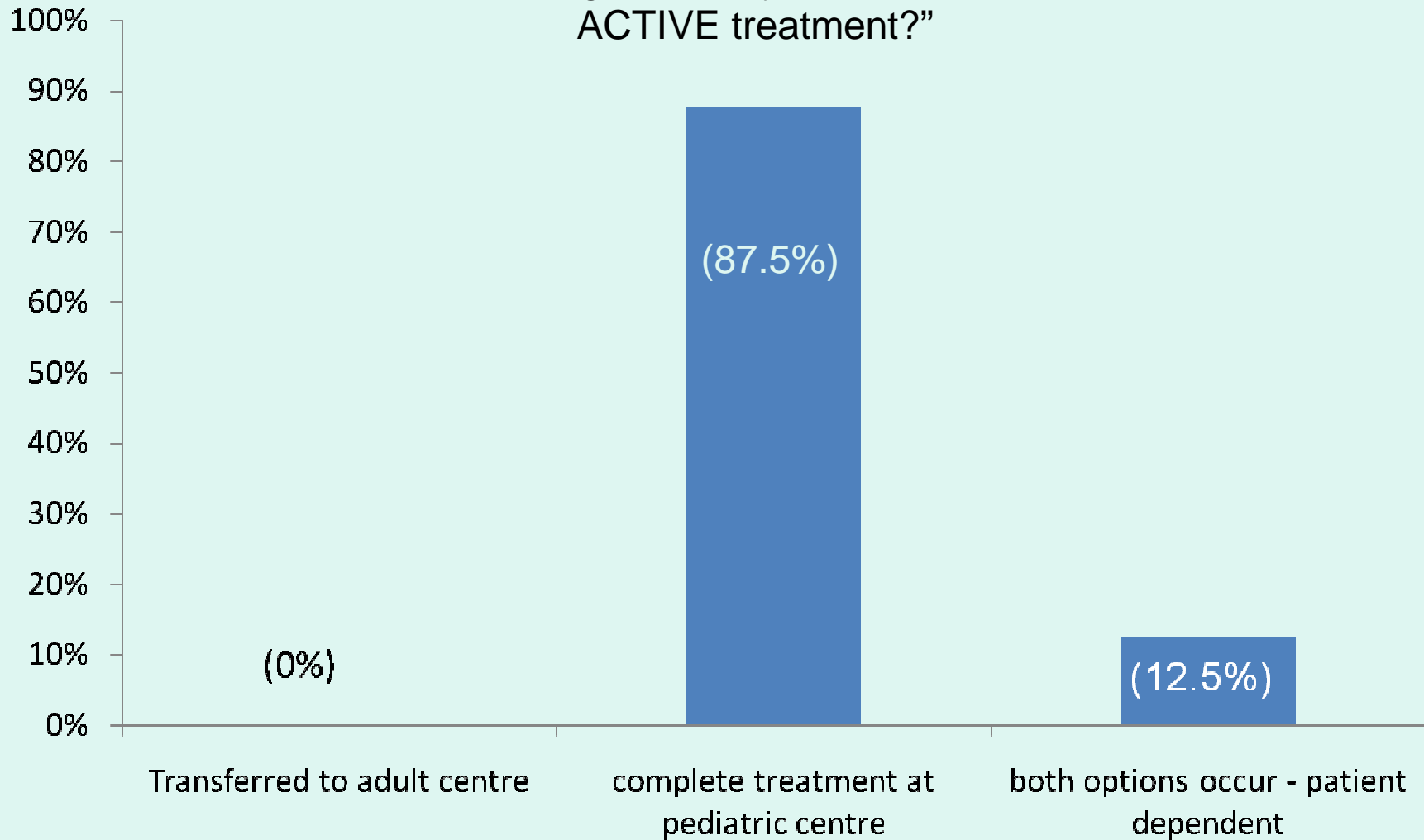


Challenges faced by institutions who reported treating patients outside their institutional age limit



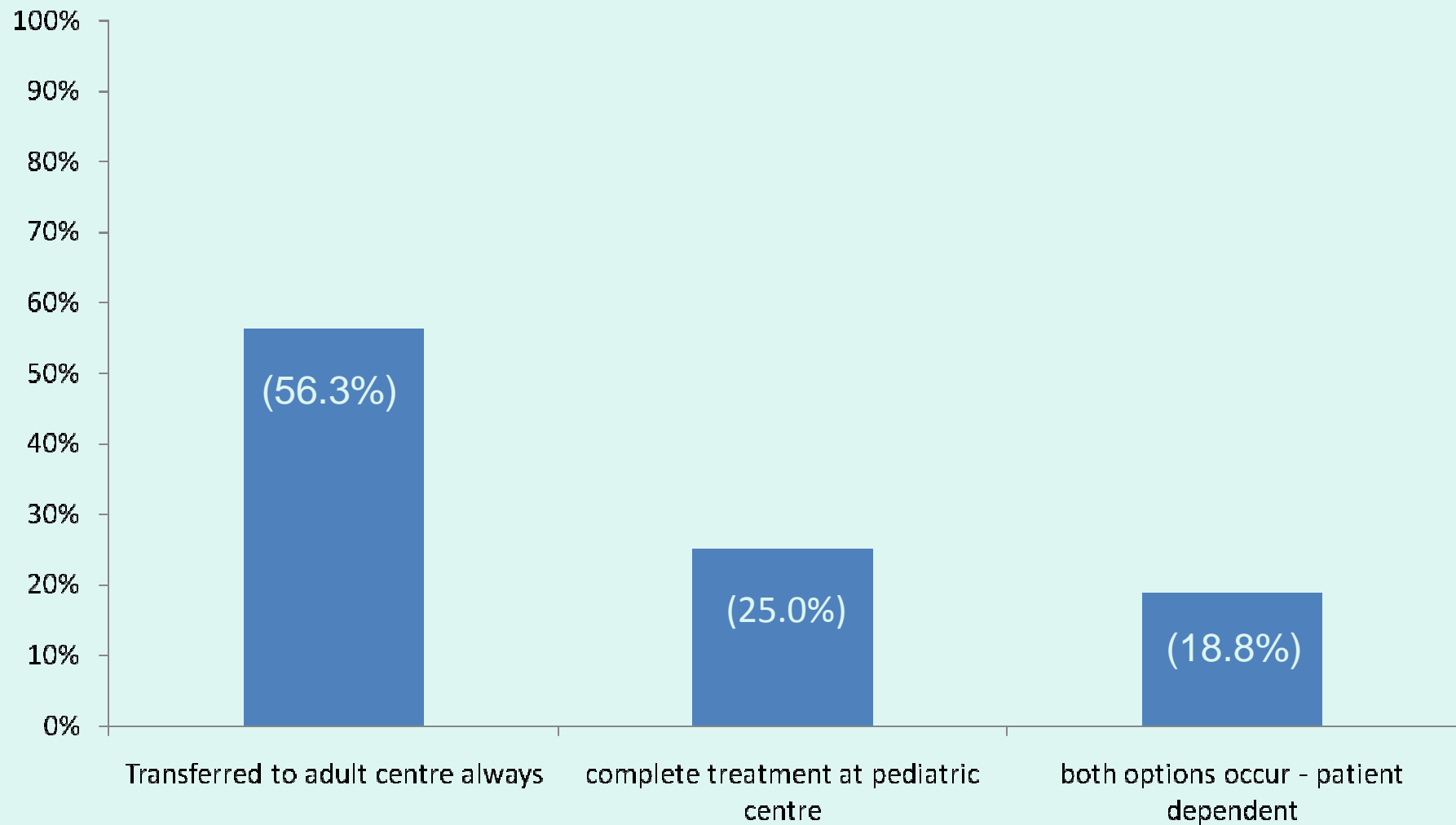
PEDIATRIC ONLY

“Which one of the following usually happens when patients reach the upper age limit at your institution while still on ACTIVE treatment?”



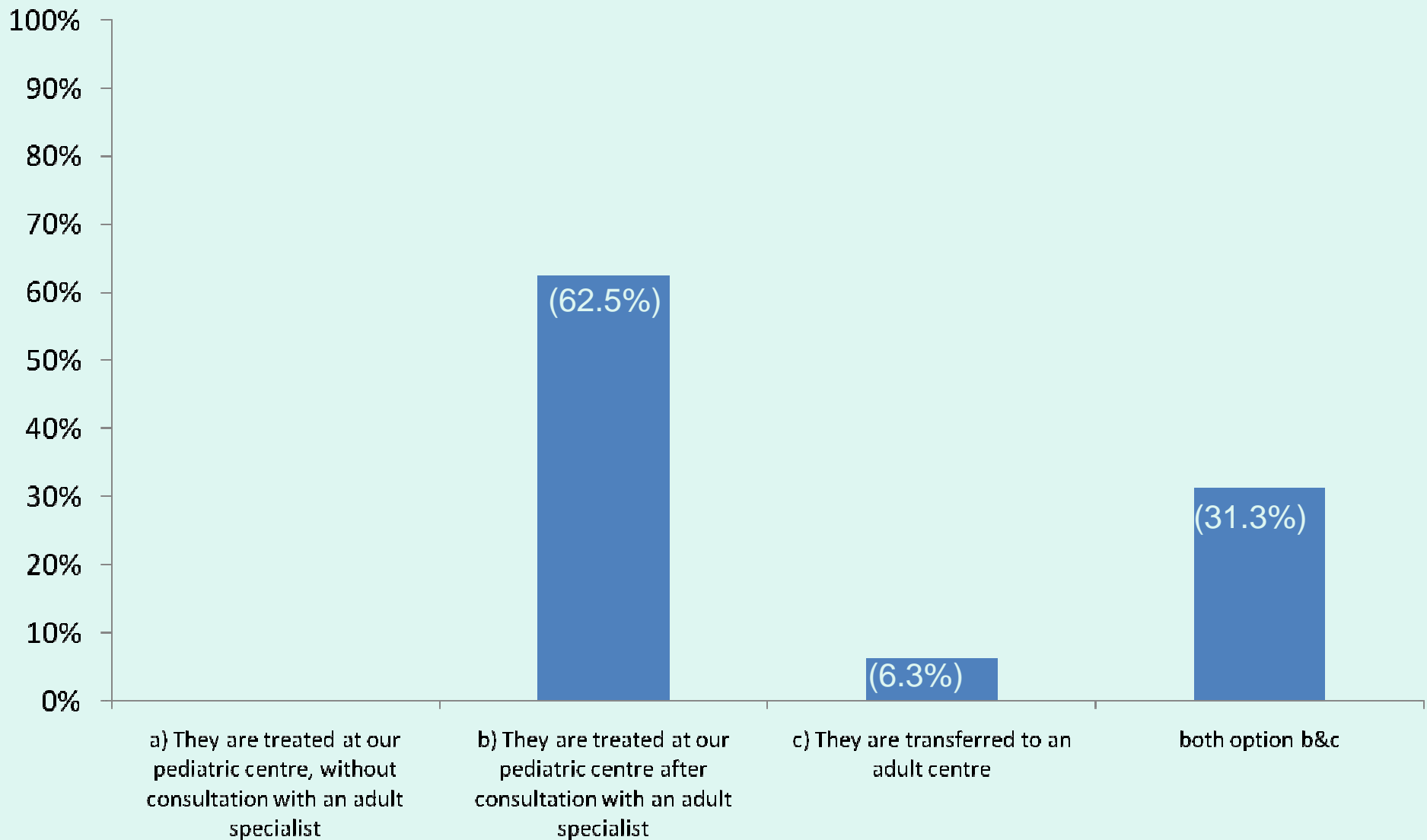
PEDIATRIC ONLY

“Which one of the following usually happens to patients who have COMPLETED treatment at your institution but RELAPSE and are over your upper age limit?”

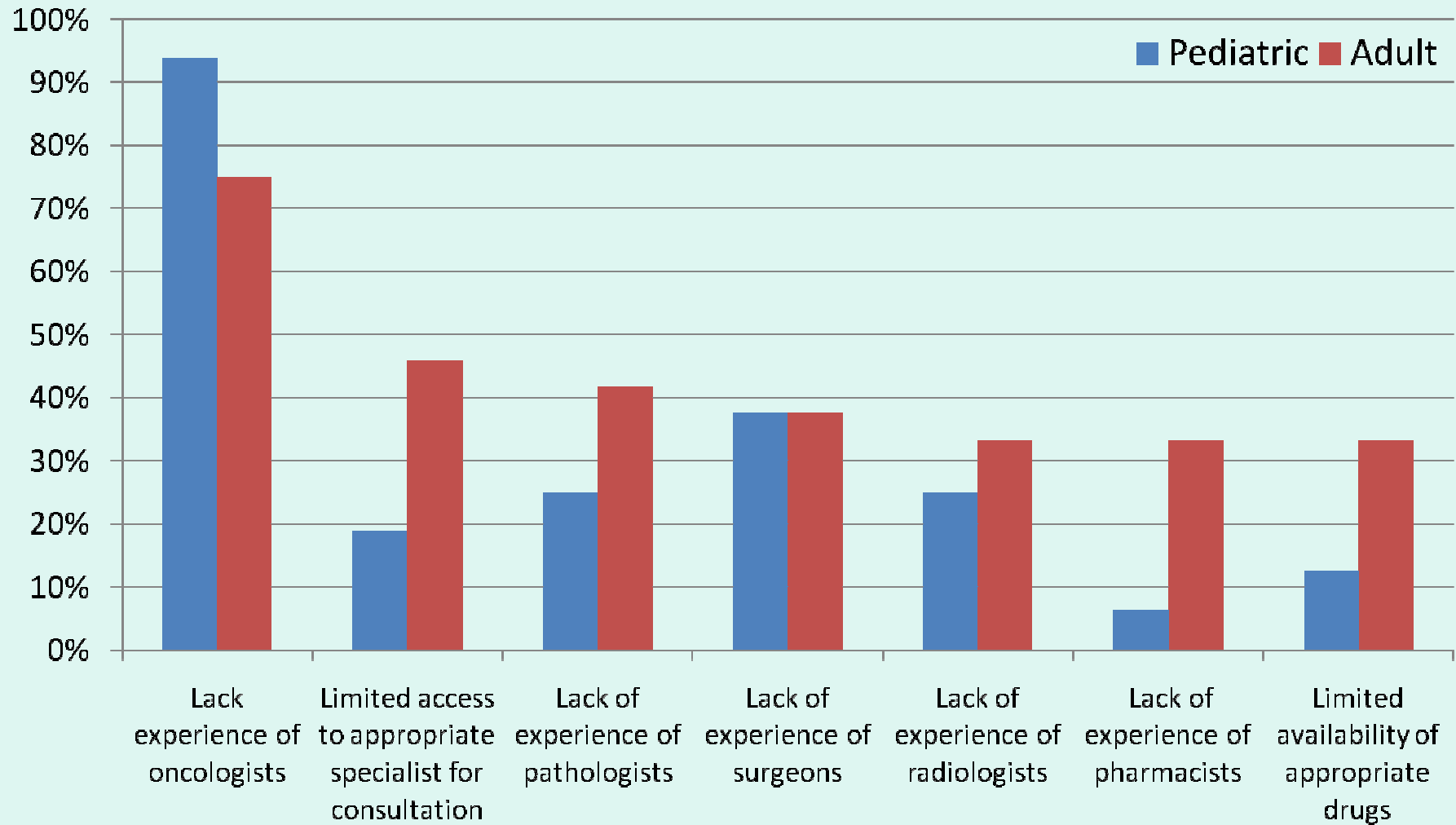


PEDIATRIC ONLY

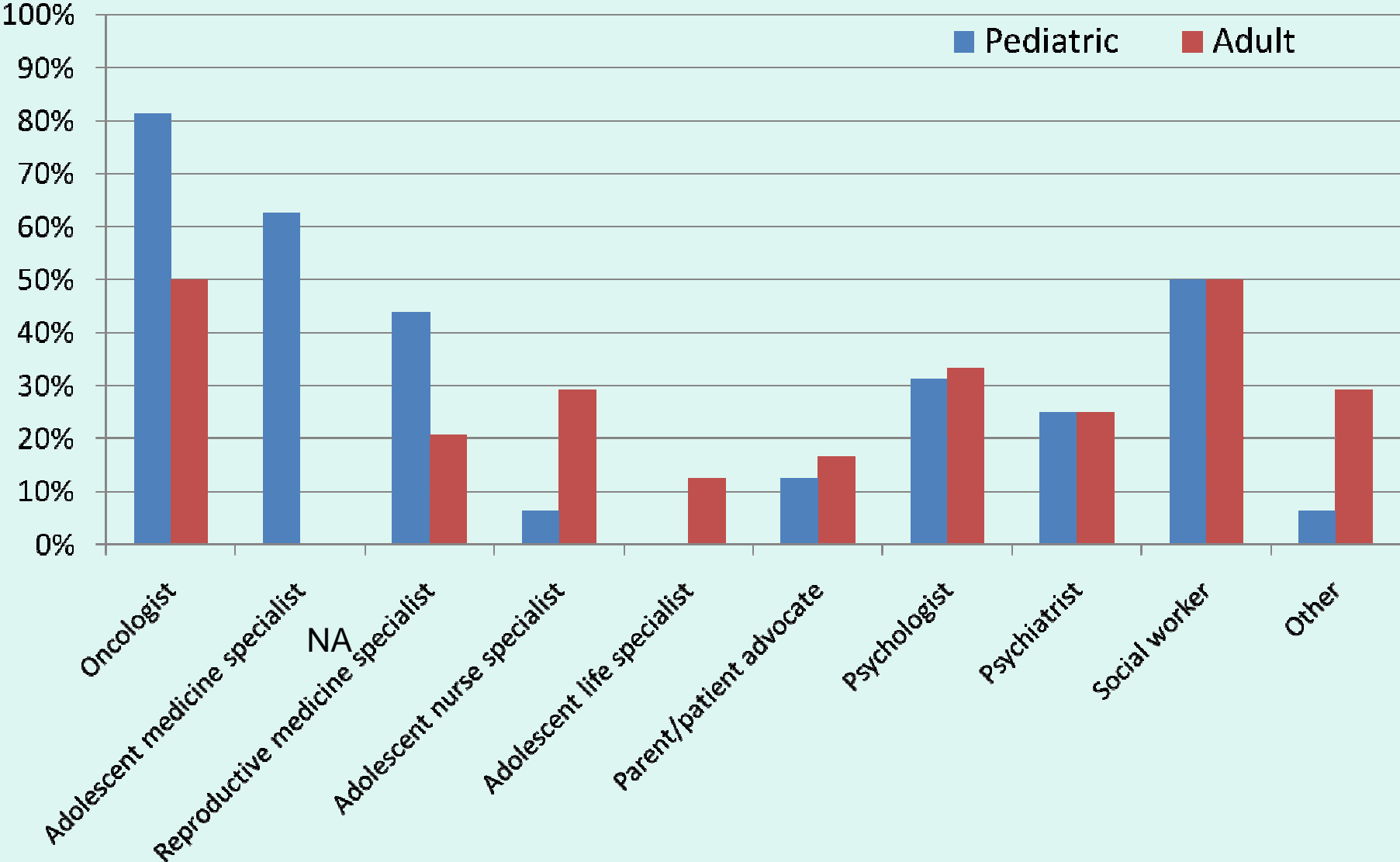
How does your service usually deal with AYA patients who present with ADULT TYPE cancers?



% of institutions who deem factor important to the diagnosis and treatment of AYA with pediatric/adult cancer

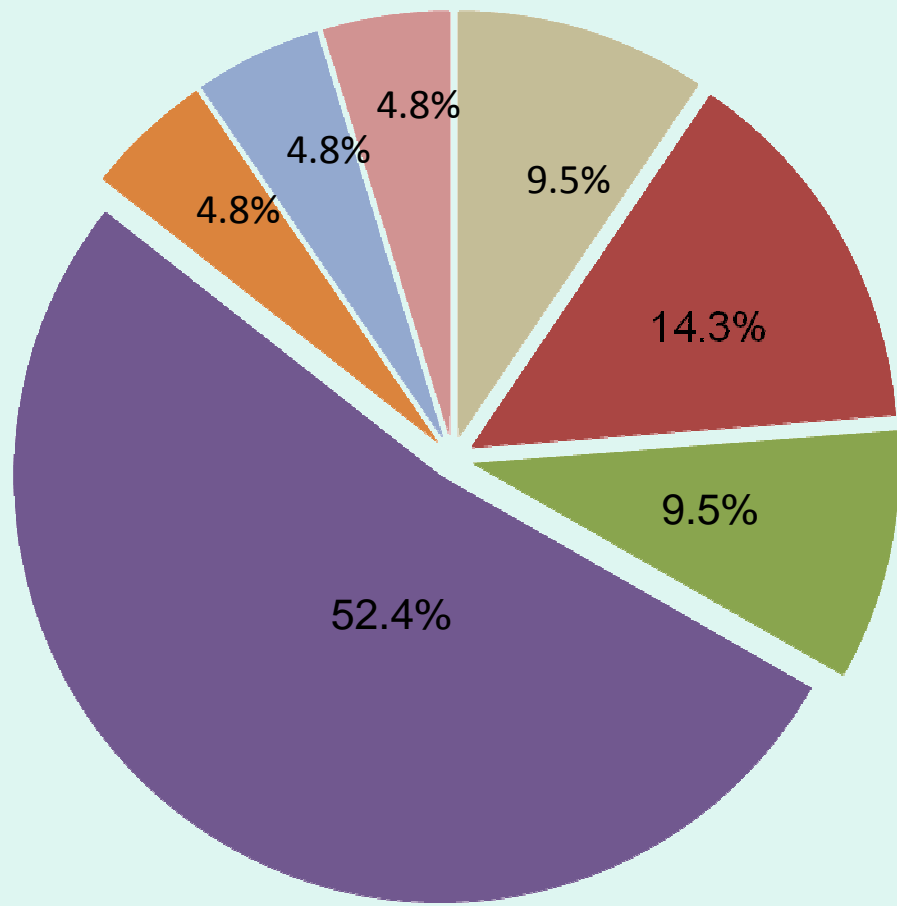


Staff with special expertise or interest in AYA



ADULT ONLY

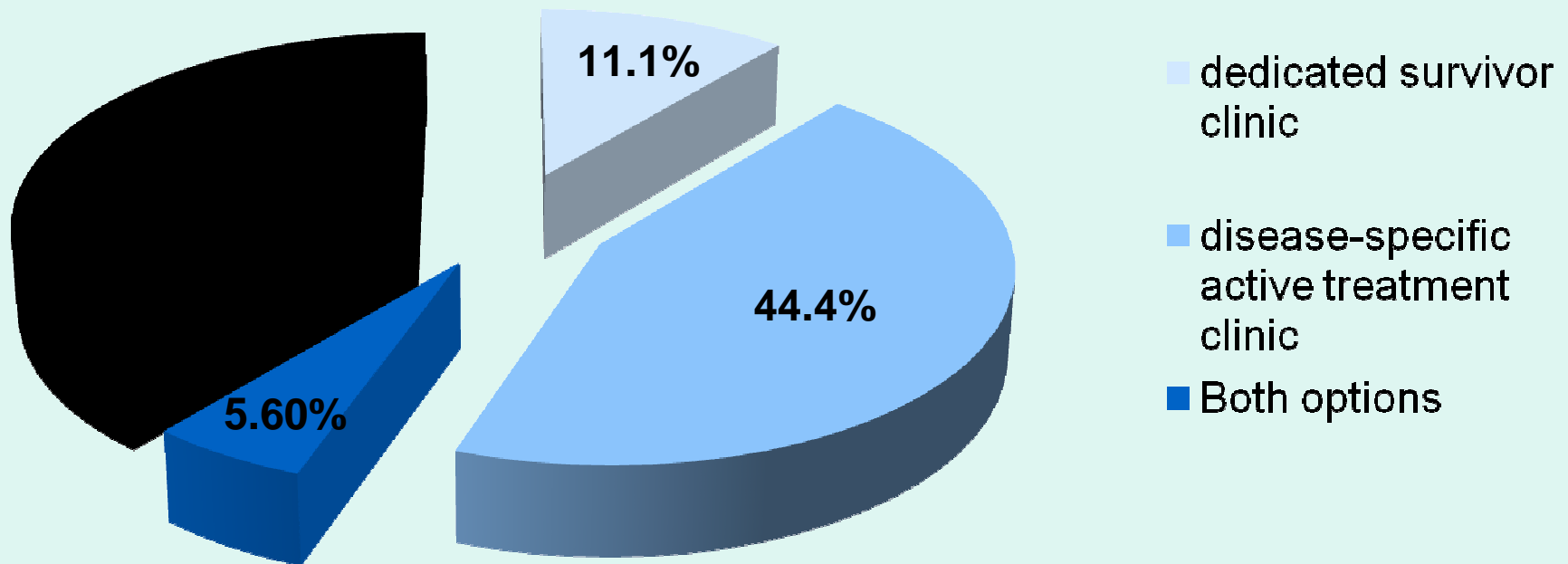
Which best describes your facility's usual plan for follow-up care of AYA who have received all or a part of their cancer therapy at your facility, after the conclusion of their active treatment?



- 1. followed in dedicated survivor clinic
- 2. followed in a disease-specific active treatment clinic
- 3. discharged and transferred back to their family physician
- 4. followed periodically in active treatment clinic but are also followed by their family physician
- 5. discharged from cancer centre without a formal plan for follow-up care
- other mechanism
- both option 1 and 2
- both option 2 and 3

ADULT ONLY

Where are patients seen in your facility : for patients who received all therapy at a pediatric centre?



Conclusions

- The recognition that AYA patients are a “Lost Tribe” is more embraced by the pediatric institutes than the adult institutes.
- The relative small numbers of AYA patients make them less of a priority for scarce resources.
- There is a wide diversity of care and service models across Canada for AYA patients with cancer and survivors of Childhood and AYA Cancers.

NEXT STEPS

- Organize 2010 workshop of stakeholders & expert advisors
- Develop recommendations & models of care at 2010 workshop
- Development of AYA research priorities
- Creation of alliance of stakeholders to ensure implementation & sustainability of efforts to improve AYA cancer care and follow up of childhood and AYA survivors.

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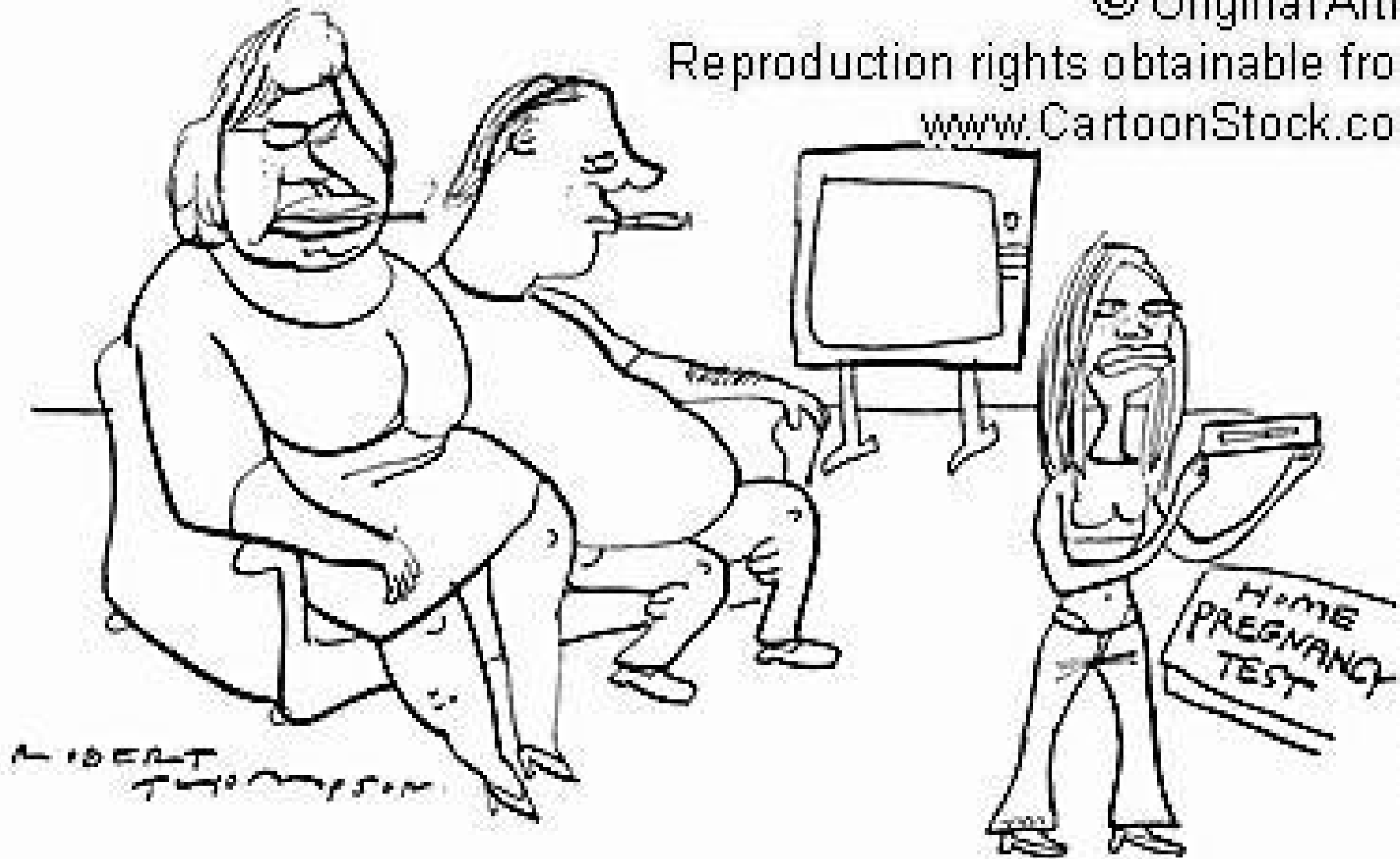
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Co-ordinator

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"I feel sorry for kids these days -
they're always being tested for something."