

# Childhood cancer survivors

## New follow-up clinic in Iceland



PNAE meeting in Iceland  
October 17, 2017

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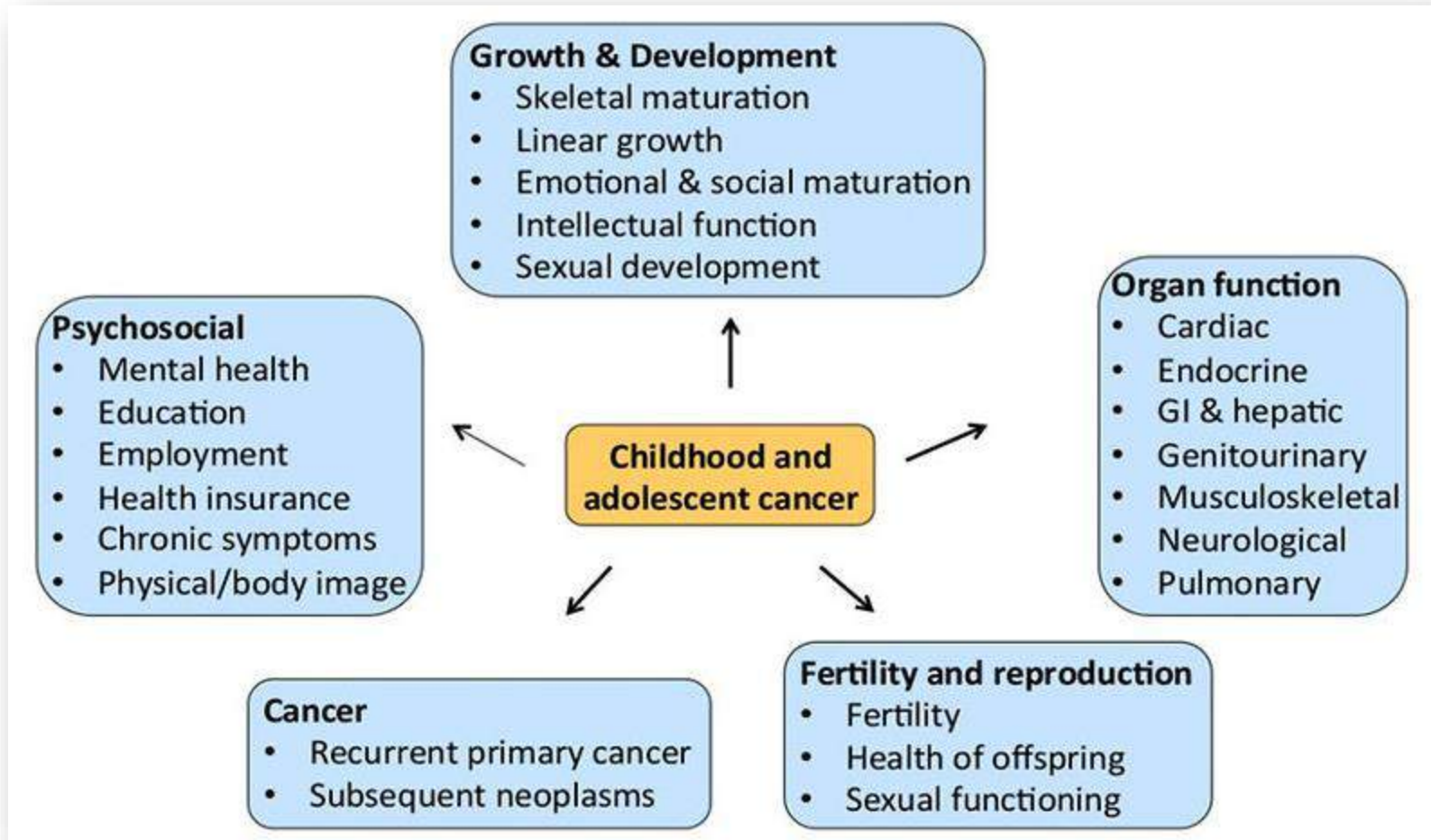




The new follow-up clinic for childhood cancer survivors in Iceland is a project funded by the Icelandic Childhood Cancer Foundation for three years

# Childhood cancer

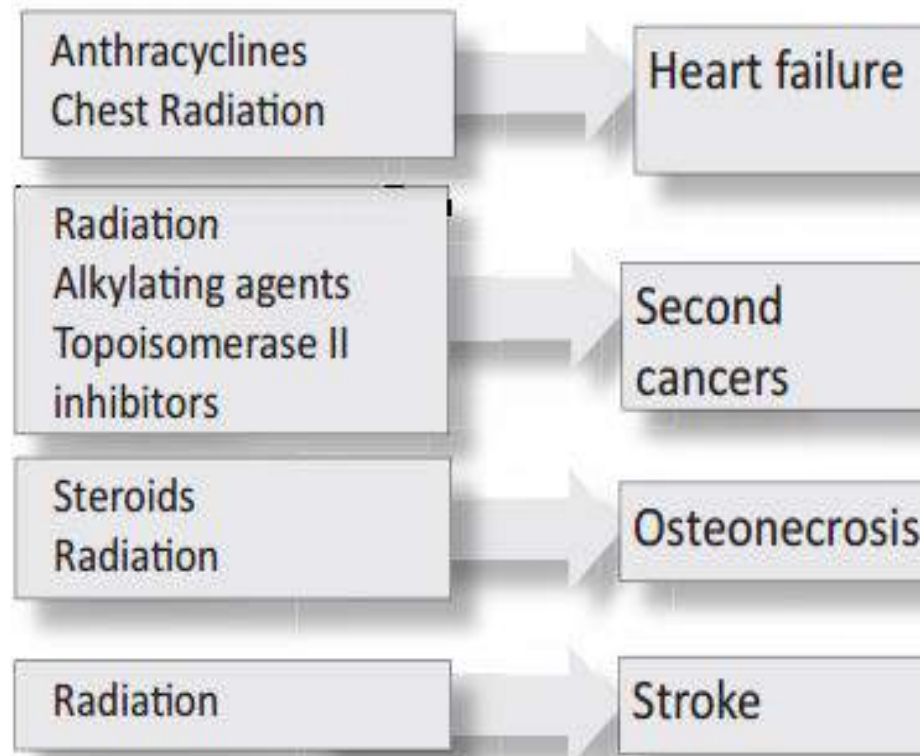
- The incident for malignancies from birth to 18 years old each year in Iceland is around 15/100.000 (10-12 children each year)
- With improvements in cancer treatment and supportive care, the survival of children and adolescents diagnosed with cancer has increased by 40% over the last four decades with the compiled five-year survival rate now being approximately 80%
- Growing number of individuals who are likely to experience some degree of adverse health consequences and quality of life issues because of the cancer treatment



**Some of the issues that are faced by survivors of childhood cancers**

(Robison & Hudson, 2014, p. 43)

# Specific cancer treatments have been linked to specific long-term health complications

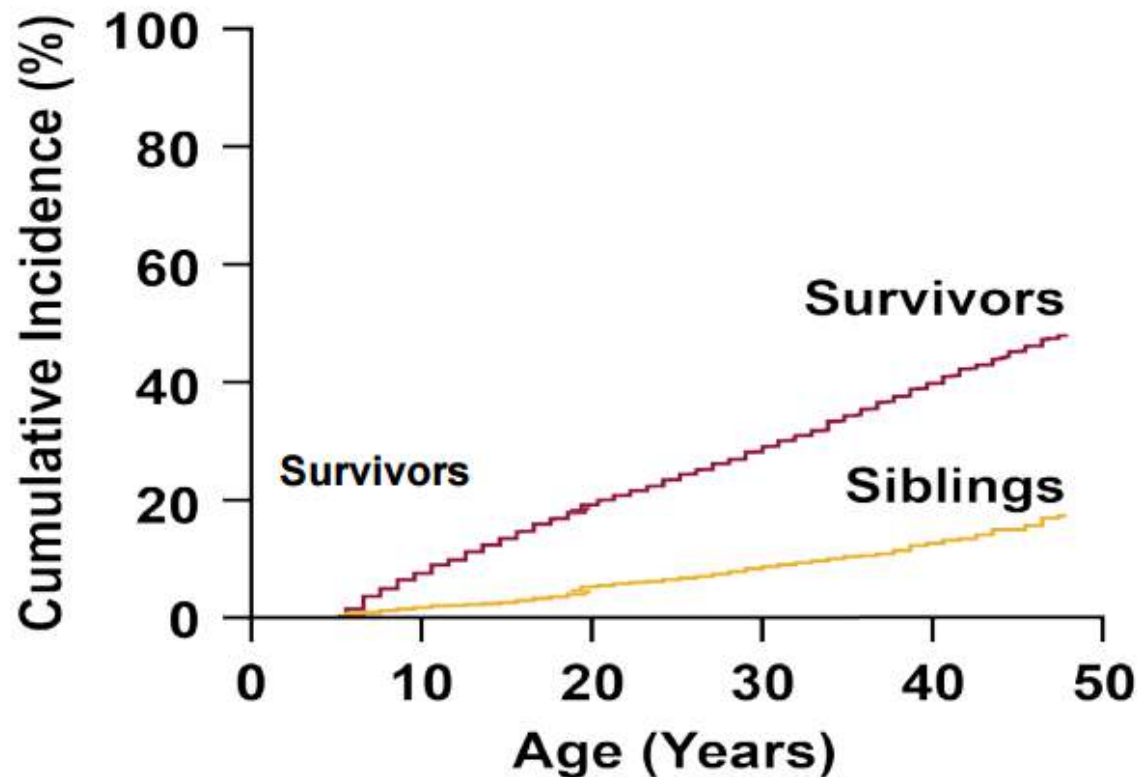


**FIGURE 3** Therapeutic exposures and adverse events. Specific cancer treatments have been linked to specific long-term health complications.

SOURCE: Bhatia presentation, March 9, 2015.

# Aging and risk of severe, disabling, life-threatening, and fatal events in the childhood cancer survivor study

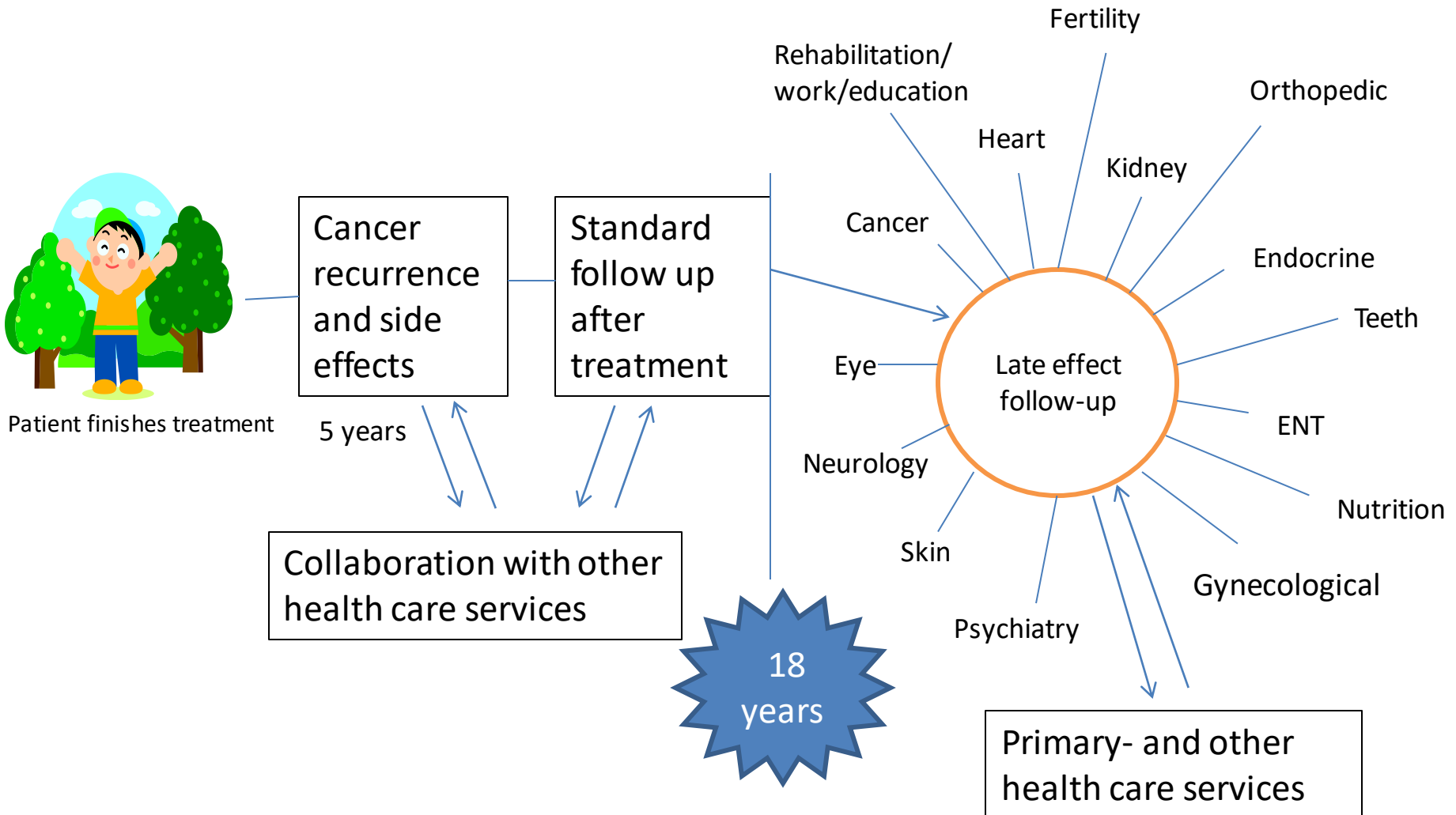
(treatments USA 1970-1986)



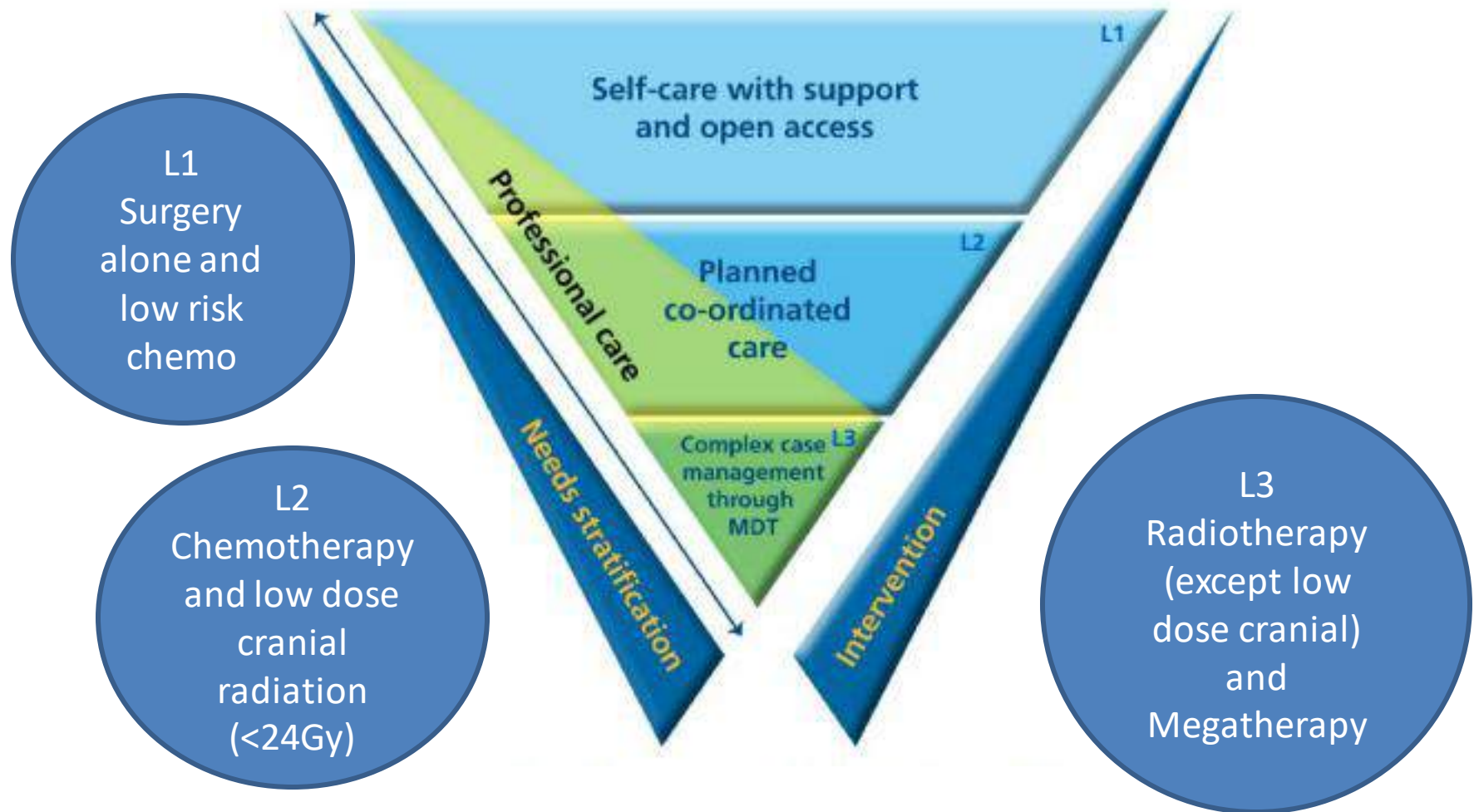
(Armstrong et.al., 2014)

# Follow-up after childhood cancer

## The Gothenburg model



# The british model



**Models of care to achieve better outcomes for children and young people living with and beyond cancer.**

(NHS Improvement, 2011, page 27)





# Guidelines for support

- International Guideline Harmonization Group for Late Effects of Childhood Cancer
- Swedish guidelines regarding follow up and survivorship passport

# Follow up in Iceland - For whom?

- From 18 to 25/30 years old
- Cancer diagnosed before 18 years
- Treatment finished 2-5 years ago
- Cured from cancer/treatment finished
- Treatment from 1981

# Who are we?

- The follow-up is prepared by a nurse and doctors from the pediatric oncology team
- References to professionals within the adult service, inside and outside the hospital, are a big part of the follow-up

# How often?

- Individualized!
- For many a regularly follow-up every 1-2 years until 25-30 years of age
- Those who are over 25 years old and were treated in 1981 or later are invited to come for at least one visit

# Purpose of follow-up

- **Improve health and quality of life** with risk based health assessment, support and education
- Give informations regarding common late effects after certain treatments – **Survivorship passport!**
- Increase the likelihood of detecting late effects early and advise on timely interventions
- Establish continued health surveillance
- Promote healthy living

# Survivorship passport

- Contains informations regarding the cancer diagnose and treatment

The passport is intended to empower people after treatment



- The **purpose** of the passport is to **support individualized long-term follow-up** by informing survivors and health care providers about:
  - possible health related risk after treatment
  - how often and what kind of health assessment is needed
  - ways to keep better health

## Before the visit:

- Asked to participate in a **study** before coming – online questionnaire (RedCap)
- Make **passport**
- Send home **AYA** psychosocial screening tool
- Blood and urine sample the week before

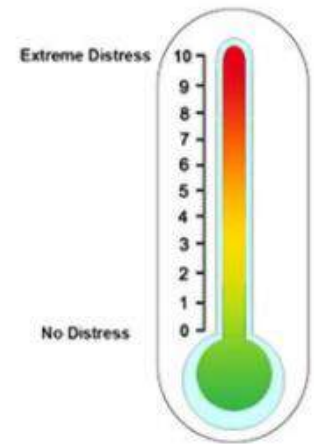


# Adolescent and Young Adult Psychosocial Survivorship Screening Tool (AYA)

- Developed in Australia - adapted from the NCCN distress thermometer 2011
- To help identify topics to be addressed in the follow-up and to guide the care plan for survivors aged 15-25 years old
- Clinicians administering this tool have as a minimum a degree in nursing, psychology, social work or medicine

# AYA

**Distress Thermometer:** Scores of 4 or more indicate levels of higher distress that needs more attention.



**Needs Assessment:** Physical; Emotional; Social; Concentration; Fertility; Impact of experience; Family; Lifestyle; Survivorship; Employment; Education.

**Future Goals:** Support survivors to get on with live after cancer in the best way they can.

**Information Required:** Tick box gives the survivors an opportunity to identify areas where further information is needed.

## Samantekt eftir krabbameinsmeðferð

Greining: C81.9 – Hodgkins disease, unspecified Classical nodular sclerosis	Stigun: II-B
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14 ára við greiningu



Dagsetning greiningar:	Dagur 1.	Mánuður Desember	Ár 1992
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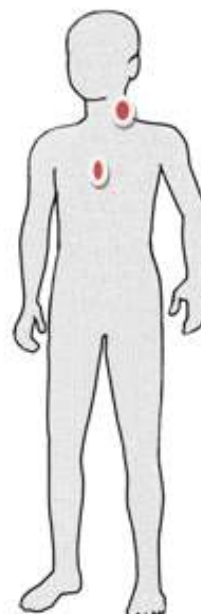


Staðsetning, sjá mynd

Eitlastækkarnir vinstra megin á halsi og í miðmæti.

Meðferð

Meðferðarskemi:	ABDV
Byrjaði:	5. desember 1992
Lök:	6. júlí 1993



Aðgerð	<input checked="" type="radio"/> Já	<input type="radio"/> Nei	Dags.
Sýnatoka úr eitli á halsi v. megin			29.11.'92

Íhlutir	Já	Nei	Já, hvar
CVK/lyfjabrunnur	x		Hægri subclavia: 4/12 '92
Gastrostomía		x	
Ventill		x	

Tegund ventils

Krabbameinslyfjamæðferð  já  nei Byrjaði: 5. desember 1992 Lök: 6. júlí 1992

Krabbameinslyf	Samanlagður skammtur mg/m <sup>2</sup>	Athugasemdir
l.v. Vincristin 1,25mg/m <sup>2</sup> x 14	17,5 mg/m <sup>2</sup>	Protocol 1,5mg/m <sup>2</sup> , hámark 2 mg í skammti
l.v. Adriamycin 64mg/m <sup>2</sup> x 4	160 mg/m <sup>2</sup>	
l.v. Etoposid 125 mg/m <sup>2</sup> x 10	1250 mg/m <sup>2</sup>	
l.v. Decarbazin 250 mg/m <sup>2</sup> x 12	3000 mg/m <sup>2</sup>	
l.v. Cyclofosfamid 500 mg/m <sup>2</sup> x 8	4000 mg/m <sup>2</sup>	

Geislameðferð:  já  nei

Geislameðferð hófst: 12. júní 1993		Allri geislameðferð lokið: 30. júní 1993
Staðsetning:	skammtar/dagar Gy	Samanlagður skammtur Gy
Háls og brjóstsvæði	1,8 Gy x 17	= 30,6 Gy

Stofnfrumskipti: já  nei

Önnur meðferð:

P.o. Decortin H (Prednison)	= 1500 mg/m <sup>2</sup>	Protocol: 60mg/m <sup>2</sup> x 15 40 mg/m <sup>2</sup> x 15

## General recommendation

Survivors treated with anthracyclines and/or chest radiation and their providers should be aware of the risk of cardiomyopathy.

## Who needs cardiomyopathy surveillance after anthracycline chemotherapy?

Cardiomyopathy surveillance *is recommended* for survivors treated with high dose ( $\geq 250$  mg/m<sup>2</sup>) anthracyclines.

Cardiomyopathy surveillance *is reasonable* for survivors treated with moderate dose ( $\geq 100$  to  $< 250$  mg/m<sup>2</sup>) anthracyclines.

Cardiomyopathy surveillance *may be reasonable* for survivors treated with low dose ( $< 100$  mg/m<sup>2</sup>) anthracyclines.

## Who needs cardiomyopathy surveillance after anthracycline chemotherapy and chest radiation?

Cardiomyopathy surveillance *is recommended* for survivors treated with moderate-high dose anthracyclines ( $\geq 100$  mg/m<sup>2</sup>) and moderate-high dose chest radiation ( $\geq 15$  Gy).

## At what age should breast cancer surveillance be initiated?

Initiation of breast cancer surveillance *is recommended* at age 25 years or  $\geq 8$  years from radiation (whichever occurs last) for female childhood, adolescent and young adult cancer survivors treated with  $\geq 20$  Gy chest radiation.

Initiation of breast cancer surveillance *is reasonable* at age 25 years or  $\geq 8$  years from radiation (whichever occurs last) for female childhood, adolescent and young adult cancer survivors treated with 10-19 Gy chest radiation.

Initiation of breast cancer surveillance *may be reasonable* at age 25 years or  $\geq 8$  years from radiation (whichever occurs last) for female childhood, adolescent and young adult cancer survivors treated with 1-9 Gy chest radiation.

<http://www.ighg.org/>

# Research

## **Late effects in adult survivors of childhood cancer A population-based study**

Project accepted for a doctoral degree in the Faculty  
of Nursing at the University of Iceland



**AIM:** Obtain information regarding health and wellbeing of childhood cancer survivors in Iceland.

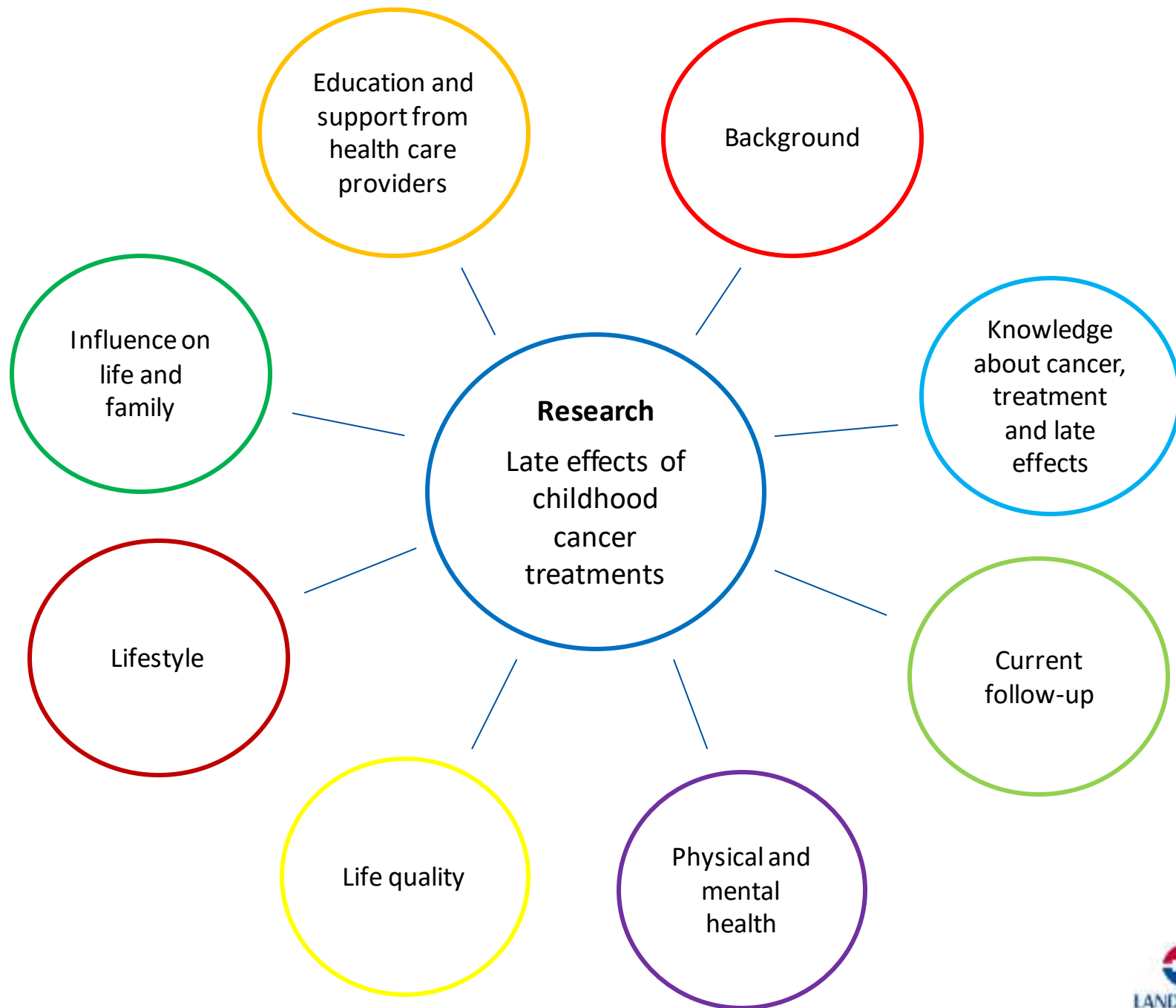
**POPULATION:** 18 years and older treated for cancer before 18 years of age in Iceland since 1981 (N = 226). Those who are invited to accept service at the late effect center are invited to participate.

**METHOD:** Observational design and mixed approach.

**BENEFIT:** Studies support mapping consequences of treatment and help to meet the needs of this group. No such study has been conducted on the Icelandic population.







## **With longer survival, studies provide important knowledge concerning both late effects and the wellbeing of survivors**

- Studies give healthcare professionals a glimpse of what to expect for certain types of cancer treatment and therefore make long-term follow-up more effective.
- Studies can also affect future protocol changes, in some cases by reducing the doses of drugs that have been associated with serious health problems.
- As long as cancer treatments continue to change, research will be a necessary part of childhood cancer survivors follow-up.



**Enjoy Iceland**

# Resources

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