

Childhood cancer survivors

New follow-up clinic in Iceland



PNAE meeting in Iceland
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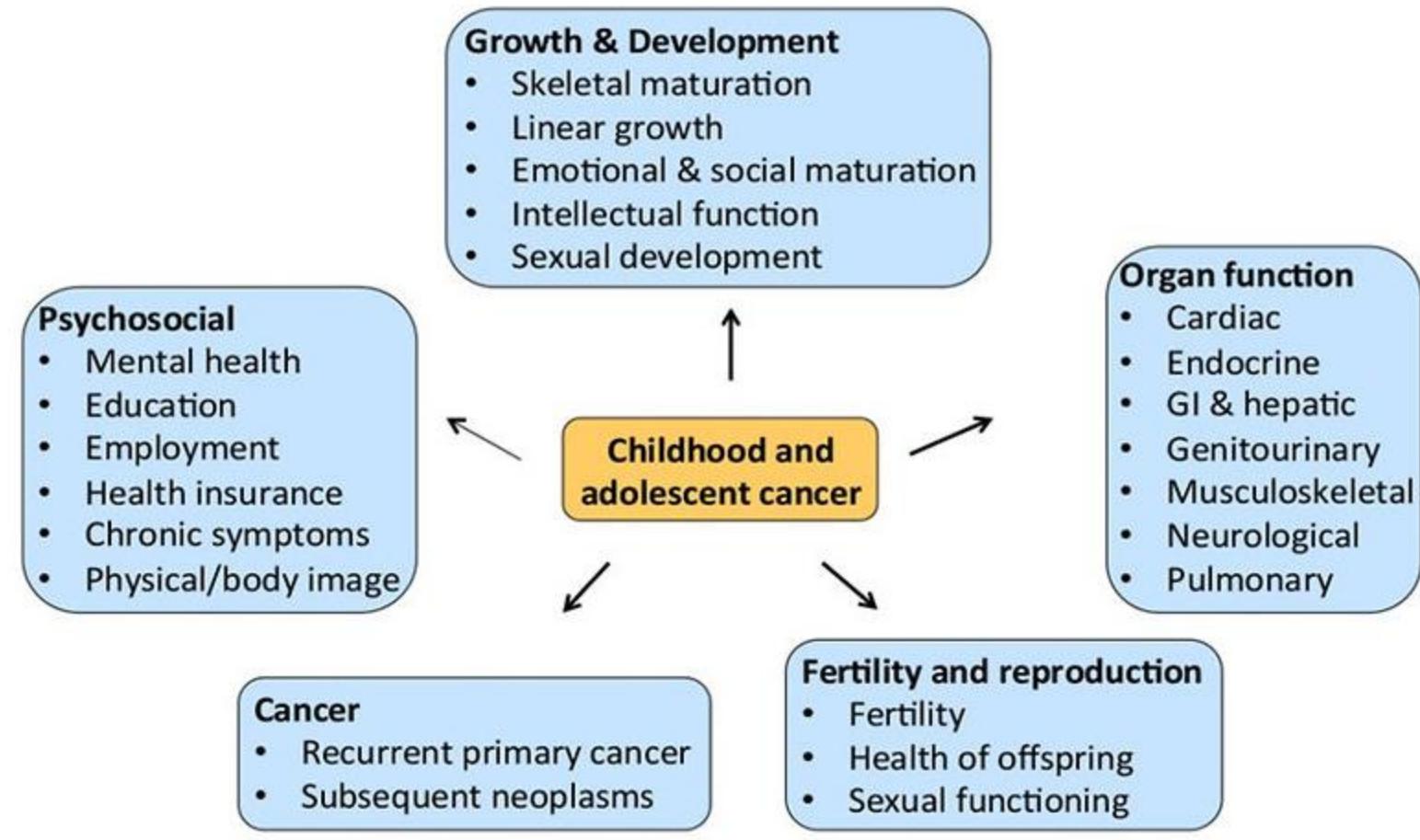


The new follow-up clinic for childhood cancer survivors in Iceland is a project funded by the Icelandic Childhood Cancer Foundation for three years

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

(Offinger, 2006; Robison & Hudson, 2014; Trausti Óskarsson et.al., 2010a).



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

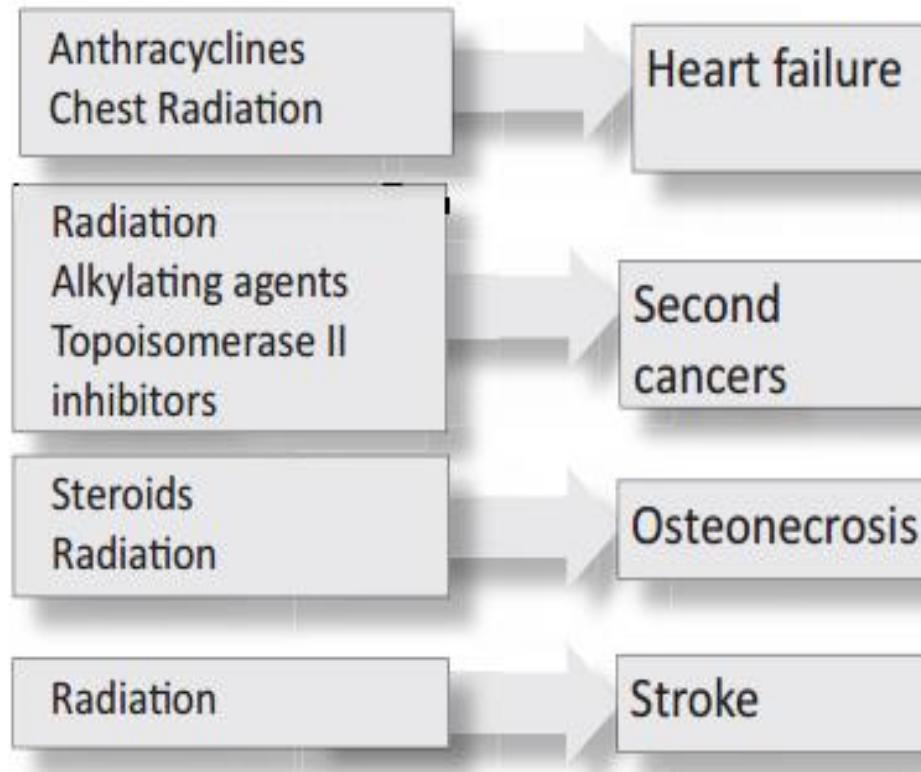
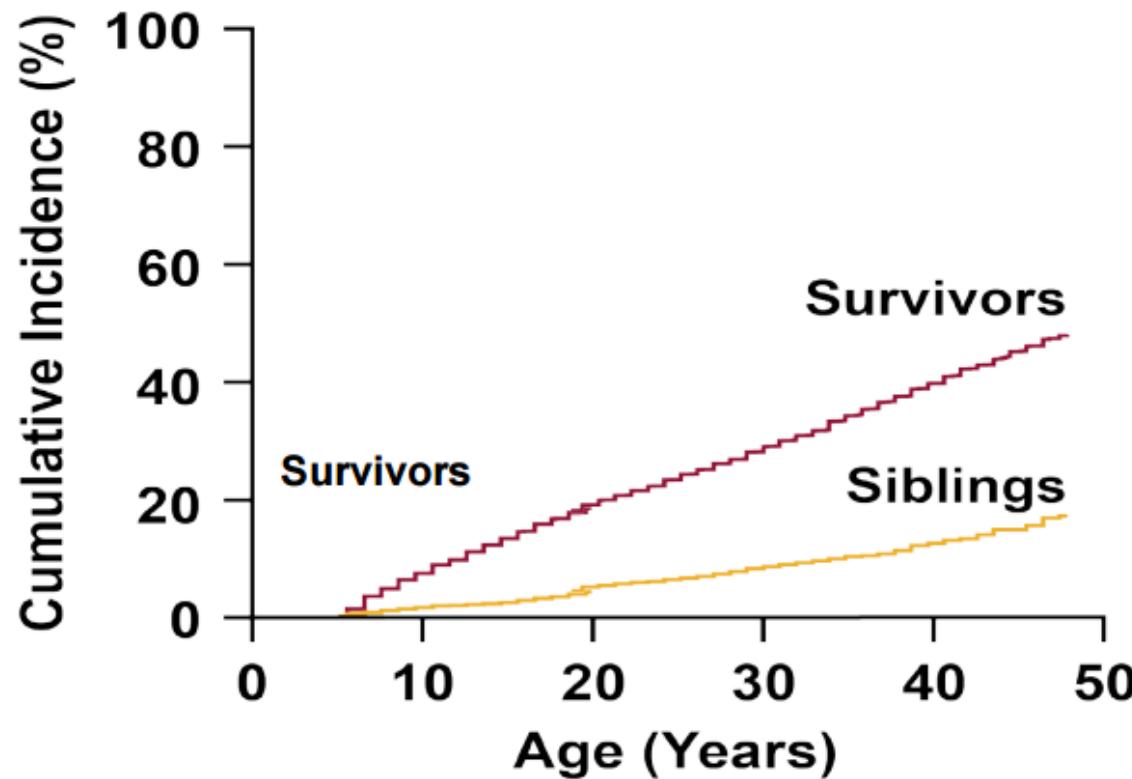


FIGURE 3 Therapeutic exposures and adverse events. Specific cancer treatments have been linked to specific long-term health complications.

SOURCE: Bhatia presentation, March 9, 2015.

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

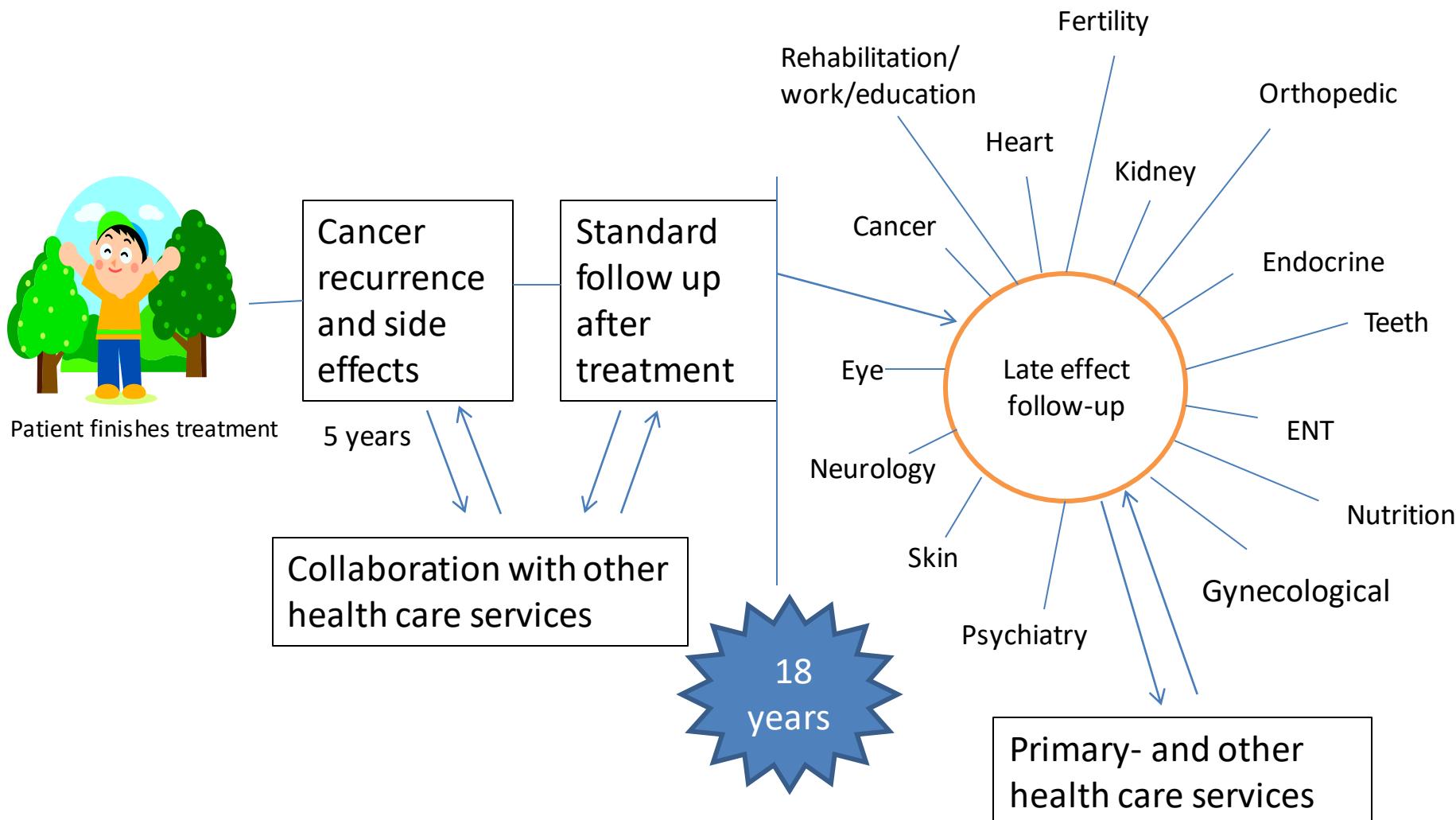
(treatments USA 1970-1986)



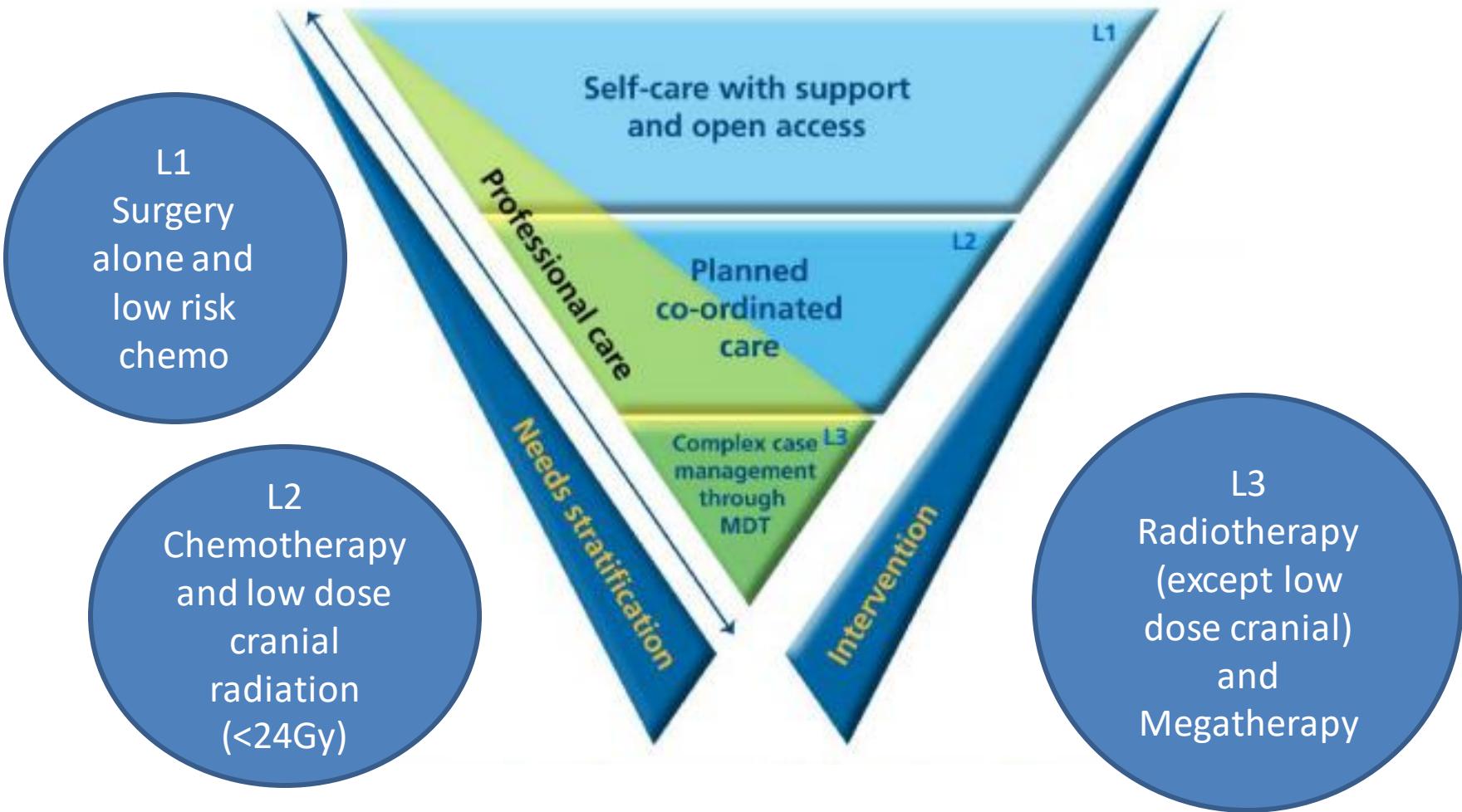
(Armstrong et.al., 2014)

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:

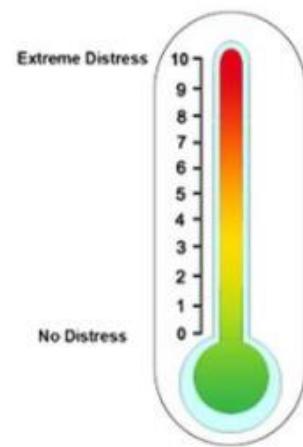
- Asked to participate in a **study** before coming – online questionnaire (RedCap)
- Make **passport**
- Send home **AYA** psychosocial screening tool
- Blood and urine sample the week before

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 life 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:	C.81.9 – Hodgkins disease, unspecified Classical nodular sclerosin	Stigun:
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14 ára við greiningu



Dagsetning greiningar:	Dagur 1.	Mánuður Desember	Ár 1992
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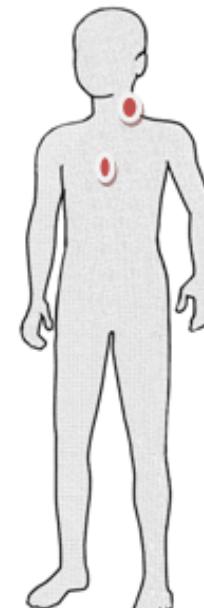


Staðsettning, sjá mynd

Eitlastækkanir vinstra megin á halsi og í miðmæti.
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Meðferð

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



Aðgerð	já	nei	Dags.
Sýntaka úr eitli á halsi vi. megin	29.11.'92		

íhlutir	já	nei	já, hvor
CVK/lyfjabrunnur	x		Hægri subclavia: 4/12 '92
Gastrostomia		x	
Ventil		x	Tegund ventils

Krabbameinslyfjameðferð

ja

nei

Byrjaði: 5. desember 1992

Lauk: 6. júlí 1992



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

Geislameðferð:

ja

nei

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

Stofnfrumuskipti:

ja

nei

Önnur meðferð:

P.o. Decortin H (Prednison)	= 1500 mg/m ²	Protocol: 60mg/m ² x 15 40 mg/m ² 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 (≥ 250 mg/m²) anthracyclines.

Cardiomyopathy surveillance is reasonable for survivors treated with moderate dose (≥ 100 to < 250 mg/m²) anthracyclines.

Cardiomyopathy surveillance may be reasonable for survivors treated with low dose (< 100 mg/m²) anthracyclines.

Who needs cardiomyopathy surveillance after anthracycline chemotherapy and chest radiation?

Cardiomyopathy surveillance is recommended for survivors treated with moderate-high dose anthracyclines (≥ 100 mg/m²) and moderate-high dose chest radiation (≥ 15 Gy).

At what age should breast cancer surveillance be initiated?

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

Initiation of breast cancer surveillance *is reasonable* at age 25 years or ≥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 ≥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



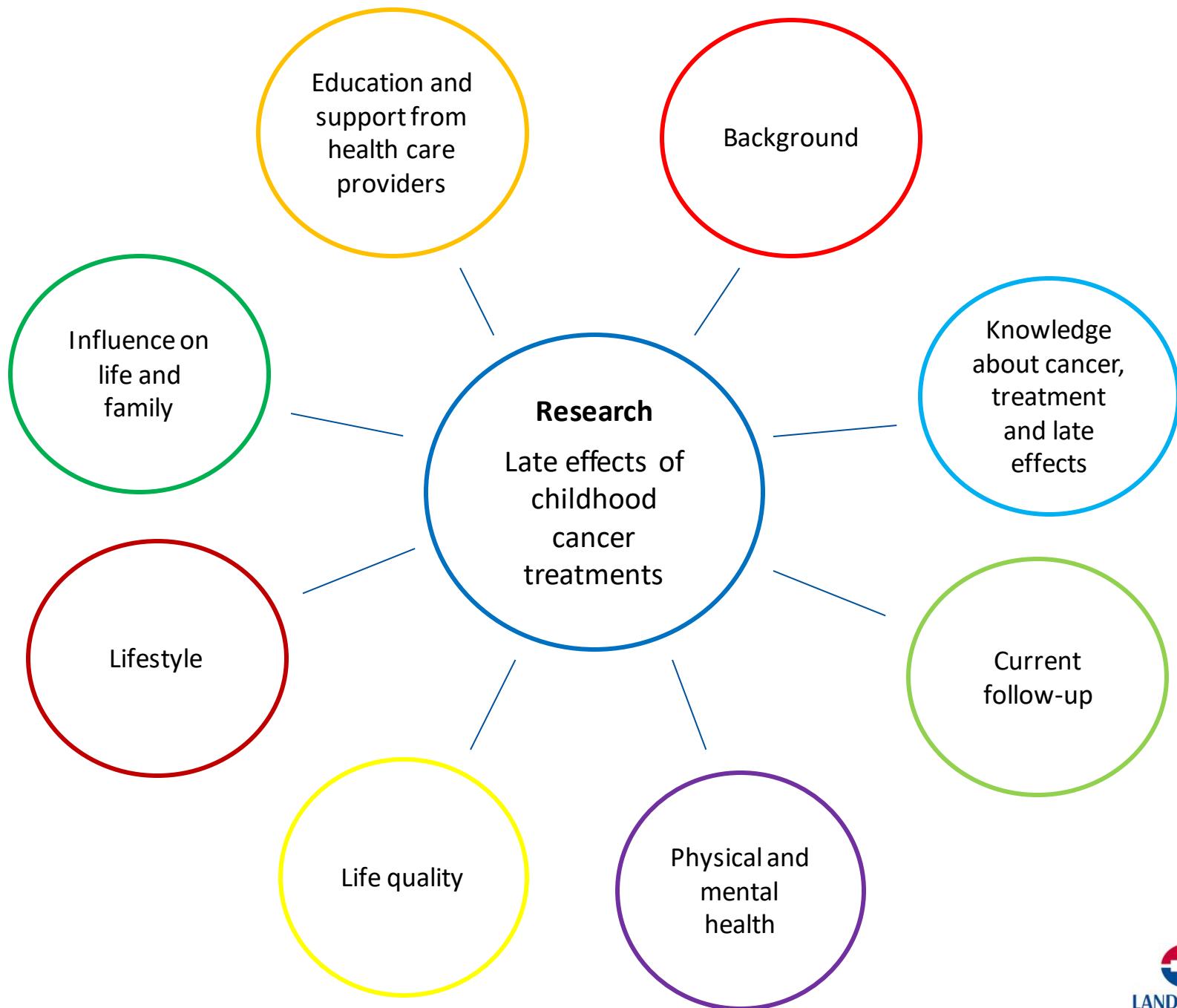
AIM: Obtain information regarding health and wellbeing of childhood cancer survivors in Iceland.

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.

A landscape photograph of Kirkjufell mountain in Iceland at night. The sky is filled with vibrant green and blue aurora borealis (Northern Lights) swirling across the dark blue night sky. In the foreground, there's a body of water reflecting the light, and some icebergs or frozen structures are visible on the left. The mountain itself is dark and silhouetted against the bright lights of the aurora.

Enjoy Iceland

Resources

Armstrong, G. T. et.al. (2014). Aging and risk of severe, disabling, life-threatening, and fatal events in the Childhood Cancer Survivor Study. *Journal of Clinical Oncology*, 32(12), 1218-1227.

Children's Oncology Group (2007). Establishing and Enhancing Services for Childhood Cancer survivors: Long-Term Follow-Up Program Resource Guide.

Kremer, L. C. M., Mulder, R. L., Oeffinger, K. C., Bhatia, S., Landier, W., Levitt, F., Constine, L. S. et.al. (2013). A Worldwide Collaboration to Harmonize Guidelines for the Long-Term Follow-Up of Childhood and Young Adult Cancer Survivors: A Report From the International Late Effects of Childhood Cancer Guideline Harmonization Group. *Pediatric Blood Cancer*, 60(4), bls. 543-549. doi: 10.1002/pbc.24445.

Nass, S. J. & Patlak, M. (2015). *Comprehensive Cancer Care for Children and Their Families: Summary of a Joint Workshop by the Institute of Medicine and the American Cancer Society*. National Academic press: Washington.

NHS improvement (2011). Models of care to achieve better outcomes for children and young people living with and beyond cancer.

Oeffinger, K. C., Mertens, A. C., Sklar, C. A., Kawashima, T., Hudson, M. M., Meadows, M. D., et.al. (2006). Chronic Health Conditions in Adult Survivors of Childhood Cancer. *The New England Journal of Medicine*, 355(15), bls. 1572-1582.

Robison, L. L. & Hudson, M. M. (2014). Survivors of childhood and adolescent cancer: life-long risks and responsibilities. *Nature Reviews Cancer*, 14, bls. 61-70. doi:10.1038/nrc3634.

Óskarsson, T., Jónsson, Ó. G., Kristinsson, J. R., Jónmundsson, G. K., Jónasson, J. G. & Haraldsson, Á. (2010). Krabbamein hjá börnum á Íslandi árin 1981-2006. *Læknablaðið*, 01(96), 21-26.