# uniform collection and central storage of data and body material for the multidisciplinary cooperative SKION-LATER group

Published: 18-05-2009 Last updated: 06-05-2024

To support future scientific research into late effects of treatment for childhood cancer

Ethical review	Approved WMO
Status	Pending
Health condition type	Other condition
Study type	Observational invasive

# Summary

### ID

NL-OMON33692

**Source** ToetsingOnline

**Brief title** SKION LATER registry and biobank

### Condition

• Other condition

**Synonym** late effects of treatment for childhood cancer

#### **Health condition**

de registratie en biobank zijn ondersteunende structuren voor wetenschappelijk onderzoek naar breed scala van late effecten

#### **Research involving**

Human

1 - uniform collection and central storage of data and body material for the multidi ... 4-05-2025

## **Sponsors and support**

Primary sponsor: Academisch Medisch Centrum Source(s) of monetary or material Support: KWF Kankerbestrijding en Stichting KIKA

### Intervention

Keyword: body material, data, late effects, pediatric oncology

### **Outcome measures**

#### **Primary outcome**

NA

#### Secondary outcome

NA

# **Study description**

#### **Background summary**

Survival rates for childhood cancer have risen beyond 75%; unfortunately, a growing number of long-term survivors of these diseases are faced with adverse health effects from their cancer treatments. Seven Dutch centers for pediatric oncology and stem cell transplantation have joint forces in a multidisciplinary cooperative group called LATER: Late Effects following childhood cancer treatment, within the pre-exisiting structures of the Dutch Childhood Oncology Group (DCOG).

The goals are defined as follows: to offer adequate patientcare for this new group of patients and to conduct scientific research into late effects of treatment for childhood cancer.

This proposal describes the DCOG-LATER registry and biobank, both intended to support future scientific research and to ameliorate patientcare for survivors of childhood cancer.

#### **Study objective**

To support future scientific research into late effects of treatment for childhood cancer

#### Study design

2 - uniform collection and central storage of data and body material for the multidi ... 4-05-2025

Cohortstudy with retrospective and prospective in-flow of childhood cancer survivors and prospective follow-up, including an extra tube of blood for the biobank.

### Study burden and risks

Burden: completion of a questionnaire and obtaining an extra tube of blood or a saliva sample

Risks: very small chance to detect yet unknown conditions ("coincidental finding") when body material is processed in the future

# Contacts

**Public** Academisch Medisch Centrum

Meibergdreef 9 1100 DD Amsterdam NL **Scientific** Academisch Medisch Centrum

Meibergdreef 9 1100 DD Amsterdam NL

# **Trial sites**

# **Listed location countries**

Netherlands

# **Eligibility criteria**

### Age

Adolescents (12-15 years) Adolescents (16-17 years) Adults (18-64 years) Children (2-11 years) Elderly (65 years and older)

3 - uniform collection and central storage of data and body material for the multidi ... 4-05-2025

# **Inclusion criteria**

- diagnosis of childhood cancer or related conditions and survival of at least 5 yrs postdiagnosis

- treated (in part) by a pediatric oncologist in one of seven participating academic hospitals
- resident of the Netherlands at the time of diagnosis
- age at diagnosis 17 years or younger

### **Exclusion criteria**

diagnosis of childhood cancer with survival less than 5 years, age at diagnosis >17 years or diagnosis while residing in foreign country

# Study design

### Design

Study type:	Observational invasive
Intervention model:	Other
Allocation:	Non-randomized controlled trial
Masking:	Open (masking not used)
Control:	Active
Primary purpose:	Other

### Recruitment

NL	
Recruitment status:	Pending
Start date (anticipated):	01-07-2008
Enrollment:	6850
Туре:	Anticipated

# **Ethics review**

Approved WMO Application type:

First submission

# **Study registrations**

## Followed up by the following (possibly more current) registration

No registrations found.

### Other (possibly less up-to-date) registrations in this register

No registrations found.

### In other registers

 Register
 ID

 CCMO
 NL23633.018.08