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A nationwide questionnaire survey on late effects among Dutch childhood cancer survivors: which invitation strategy to use?

Submission date
22/05/2014

Recruitment status
No longer recruiting

Registration date
27/06/2014

Overall study status
Completed

Last Edited
18/04/2017

Condition category
Cancer

[_] Prospectively registered
[_] Protocol
[_] Statistical analysis plan
[X] Results
[_] Individual participant data

Plain English summary of protocol

Background and study aims
Advances in the diagnosis and treatment of childhood cancer in the last decade has meant that many more children now survive the disease. Unfortunately, however, it has become increasingly apparent that both the treatment and the cancer itself can have long-term effects on health. Long-term follow-up of childhood cancer survivors (CCS) is therefore vital. The Dutch Childhood Oncology Group (DCOG) has set up a nationwide study called DCOG-LATER, which aims to identify which groups of CCS are most at risk of long-term health problems which will then form the basis of recommendations on later follow-up programmes. The study also involves research on accurate screening tests and effective treatments (interventions) that might be needed to reduce morbidity and mortality in CCS. In order for the DCOG-LATER study results to be meaningful, it is important that a representative group of CCS participate in the study. It is therefore vital to encourage as many CCS to participate as possible. Characteristics such as the age and gender of a potential participant and also what the study involves can influence whether or not they will agree to take part. The aim of this study is to investigate the effect of different invitation strategies on participation rates in a questionnaire survey among CCS. We also want to investigate reasons for non-participation, whether people prefer to complete a paper-based or web-based questionnaire and which groups of CCS (in terms of age, or gender) prefer each type of questionnaire.

Who can participate?
Adult CCS that were diagnosed with cancer before the age of 18 and between 1st January 1962 and 31st December 2001, alive 5 years after diagnosis and treated in one of the seven Dutch paediatric oncology and stem cell transplant centers. They also have to be currently living in the Netherlands.

What does the study involve?
Each participant is randomly allocated to one of three groups. All participants receive an initial invitation to take part in the study. For groups 1 and 2, two postal reminders and one telephone reminder are sent out. For group 3, only one postal reminder and one telephone reminder is sent. With each invitation, the CCS were given a web-based questionnaire. Paper-based

questionnaires are also given at various timepoints depending on group. Group 3 receive the paper-based questionnaire as part of their initial invitation, group 2 as part of the first reminder and group 1 receive their paper-based questionnaire as part of their second reminder.

What are the possible benefits and risks of participating?
Not provided at time of registration

Where is the study run from?
Academic Medical Center (Netherlands)

When is the study starting and how long is it expected to run for?
December 2012 to June 2013

Who is funding the study?
1. The Dutch Childhood Oncology Group (DCOG) (Netherlands)
2. The Children Cancerfree Foundation (KiKa) (Netherlands)

Who is the main contact?
Miss Monique Jaspers

Contact information

Type(s)
Scientific

Contact name
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Additional identifiers

Protocol serial number
131

Study information

Scientific Title
An evaluation of response rates, questionnaire mode preferences and satisfaction of Dutch childhood cancer survivors invited for the DCOG LATER study

Acronym
Dutch Childhood Oncology Group (DCOG) LATe Effects Registry (LATER) EPIdemiology (EPI)

Study objectives

The aim of the current study was to investigate the effect of different invitation strategies on participation rates in a questionnaire survey among childhood cancer survivors (CCS). In addition, we assessed reasons for non-participation, differences in participants questionnaire mode preferences and satisfaction with the different questionnaire modes.

Ethics approval required
Old ethics approval format

Ethics approval(s)
Medisch Ethisch Toetsingscommissie AMC, 27/04/2012, ref: W12_105

Study design
Multi-center randomized trial

Primary study design
Interventional

Study type(s)
Other

Health condition(s) or problem(s) studied
Childhood cancer survivors

Interventions
CCS from three centers were randomly allocated to one of three study arms on a 1:1:1 ratio. In study arms 1 and 2, two postal reminders and one telephone reminder followed the initial invitation; in the second reminder strategy (study arm 3), only one postal reminder and one telephone reminder followed the initial invitation. With every invitation, CCS received a web-based questionnaire. Paper-based questionnaires were added to the invitation at various time points depending on the study arm. CCS either received the paper-based questionnaire at the initial invitation (study arm 3), first reminder (study arm 2) or second reminder (study arm 1).

Intervention Type
Other

Phase
Not Applicable

Primary outcome(s)
Participation rates assessed 1 year after the start of the study on 01/09/2013

Key secondary outcome(s))
1. Response rates assessed 1 year after the start of the study on 01/09/2013
2. Response type assessed 1 year after the start of the study on 01/09/2013
3. Satisfaction with questionnaire
4. Reasons for completing paper- or web-based questionnaire

Completion date
01/06/2013

Eligibility

Key inclusion criteria
We randomly selected 750 adult CCS from the DCOG LATER cohort, which includes subjects diagnosed with a malignancy (or a few specific benign disorders) before the age of 18 years between 1 January 1962 and 31 December 2001, alive 5 years post diagnosis, that were treated in one of the seven Dutch paediatric oncology and stem cell transplant centers. For the current study, CCS had to be alive, aged 18 or older and living in the Netherlands.

Participant type(s)
Patient

Healthy volunteers allowed
No

Age group
Adult

Lower age limit
18 years

Sex
All

Key exclusion criteria
CCS were excluded if they lived abroad or were lost-to-follow-up

Date of first enrolment
01/12/2012

Date of final enrolment
01/06/2013

Locations

Countries of recruitment
Netherlands

Study participating centre
Meibergdreef 9
Amsterdam
Netherlands
1105 AZ

Sponsor information

Organisation
Academic Medical Center (AMC) (Netherlands)

ROR
https://ror.org/03t4gr691

Funder(s)

Funder type
Charity

Funder Name
The Dutch Childhood Oncology Group (DCOG) (Netherlands)

Funder Name
The Children Cancerfree Foundation (KiKa) (Netherlands)

Results and Publications

Individual participant data (IPD) sharing plan

IPD sharing plan summary
Not provided at time of registration

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Results article	results	24/11/2015		Yes	No
Study website	Study website	11/11/2025	11/11/2025	No	Yes