# Familieleden informeren over de kans op kanker en preventieve maatregelen.

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We aim to develop and evaluate an intervention focused at supporting counselees in disclosing information about cancer risks and preventive measures to their relatives. We assume that the intervention will increase counselees' knowledge,...

| | |
|---|---|
| **Ethische beoordeling** | Positief advies |
| **Status** | Werving gestopt |
| **Type aandoening** | - |
| **Onderzoekstype** | Interventie onderzoek |

## Samenvatting

### ID

NL-OMON25373

**Bron**
Nationaal Trial Register

**Aandoening**

Hereditary breast cancer
Hereditary colon cancer
Family communication
Genetic counseling
Relatives
Risk communication

Erfelijke borstkanker
Erfelijke darmkanker
Familiecommunicatie
Genetische counseling
Familieleden informeren
Risicocommunicatie

### Ondersteuning

**Primaire sponsor:** Academic Medical Centre
**Overige ondersteuning:** KWF cancer society

## Onderzoeksproduct en/of interventie

## Uitkomstmaten

### Primaire uitkomstmaten

1. Knowledge, which comprises:<br>
A. Insight into which relatives need to be informed;<br>
B. Risk perception;<br>
C. General knowledge about hereditary cancer;
br>
D. Knowledge about surveillance measures for relatives.<br>
2. Motivation;<br>
3. Self-efficacy.

# Toelichting onderzoek

### Achtergrond van het onderzoek

Purpose:

The identification of a hereditary or familial breast or colon cancer risk has not only implications for the counselee, but also for his or her relatives. Relatives may need to be informed about their possible risk. Based on this risk information, they can make an informed decision about whether or not to pursue genetic counseling, testing and/or preventive breast or colon screening. Genetic counselors therefore encourage counselees to discuss cancer risks and preventive measures with their relatives. However, fewer relatives present to genetic services for care than would be expected. Of at risk first degree relatives, an average of 40% present to genetic services for care. Percentages for 2nd and 3rd degree relatives are lower. The limited uptake of genetic and surveillance services raises the question whether and how at risk relatives are informed by the counselee. Literature suggests that counselees may encounter barriers in family disclosure that result from 1) lack of knowledge (e.g., not knowing who is at risk), 2) lack of motivation to inform (e.g., wanting to protect relatives for negative emotions) and 3) lack of self-efficacy, i.e., not being able to inform (e.g., loss of contact).

We aim to develop and evaluate an intervention focused at supporting counselees in disclosing information about cancer risks and preventive measures to their relatives.

Our primary research question is:

1. Does such an intervention increase counselees’ knowledge, motivation and self-efficacy with regard to disclosing information about cancer risks and preventive measures to at risk relatives?

Secondary questions are:

2. Does such an intervention:

A. Lead to counselees informing more relatives?

B. Lead to increased knowledge in relatives about hereditary or familial cancer and preventive measures?

C. Increase informed relatives’ intention to engage in genetic counseling, testing and/or preventive screening?

3. Which sociodemographic, personal, familial and clinical characteristics of counselees are associated:

A. With knowledge, motivation and self-efficacy regarding the disclosure of information about cancer risk and preventive measures to at risk relatives?

B. With the number of informed relatives?

Plan of investigation:

Counselees in the control group (n=132) will receive standard care. Counselees in the intervention group (n=132) will receive additional counseling by telephone, provided by one of five psycho-social workers, aimed at whether and how best to inform at risk relatives. This intervention will be based on the principles of Motivational Interviewing. Assessments, using questionnaires, will take place after the final regular genetic counseling session (T1), immediately following the intervention (T2) and at 4 months after the intervention (T3). At T2, a part of the questionnaire will be completed together with the researcher by phone. The primary outcomes of the study comprise the counselees’ knowledge, motivation and self-efficacy regarding the dissemination of information about cancer risk information and preventive measures into the family.

Relevance:

Genetic counselors rely on counselees to inform their relatives about their hereditary or familial cancer risk and possibilities to reduce this risk. It is therefore essential that their ability to be a competent, motivated and confident informant is maximized, while respecting their wish not to inform (some) relatives. The proposed intervention will 1) support

counselees in this difficult task and 2) hopefully allow more at risk relatives to make a well informed decision. This may lead to more relatives taking up genetic services and preventive screening, if needed. Consequently cancer morbidity and mortality will be reduced in affected families.

**Doel van het onderzoek**

We aim to develop and evaluate an intervention focused at supporting counselees in disclosing information about cancer risks and preventive measures to their relatives.

We assume that the intervention will increase counselees' knowledge, motivation and self-efficacy with regard to disclosing hereditary cancer information to at risk relatives.

**Onderzoeksopzet**

T1: Before the intervention (when counselees have received the summary letter fromt he Clinical Genetics department);

T2: After the intervention (and 4 weeks after T1 for the control group;

T3: 4 months after the intervention.

**Onderzoeksproduct en/of interventie**

The intervention consists of an additional counseling session by telephone based on the principles of Motivational Interviewing and performed by psychosocial workers.

The control group will receive care as usual.

# Contactpersonen

## Publiek

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### Wetenschappelijk

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## Deelname eisen

### Belangrijkste voorwaarden om deel te mogen nemen (Inclusiecriteria)

1. Index-patient (first in the family to visit the department of Clinical Genetics for hereditary or familial colon or breast cancer);

2. At least one relative at risk for breast or colon cancer, i.e. eligible for genetic counseling and/or surveillance;

3. Aged 18 years and over;

4. Able to read and write Dutch;

5. Informed consent.

### Belangrijkste redenen om niet deel te kunnen nemen (Exclusiecriteria)

1. Mentally impaired;

2. Unable to independently complete a questionnaire;

3. Not literate in Dutch.

# Onderzoeksopzet

## Opzet

| | |
|---|---|
| Type: | Interventie onderzoek |
| Onderzoeksmodel: | Parallel |
| Toewijzing: | Gerandomiseerd |
| Blindering: | Enkelblind |
| Controle: | N.v.t. / onbekend |

## Deelname

Nederland

| | |
|---|---|
| Status: | Werving gestopt |
| (Verwachte) startdatum: | 01-10-2012 |
| Aantal proefpersonen: | 264 |
| Type: | Werkelijke startdatum |

# Ethische beoordeling

Positief advies

| | |
|---|---|
| Datum: | 10-12-2012 |
| Soort: | Eerste indiening |

# Registraties

## Opgevolgd door onderstaande (mogelijk meer actuele) registratie

ID: 39133
Bron: ToetsingOnline
Titel:

## Andere (mogelijk minder actuele) registraties in dit register

Geen registraties gevonden.

## In overige registers

| Register | ID |
|---|---|
| NTR-new | NL3594 |
| NTR-old | NTR3745 |
| CCMO | NL40153.018.12 |
| ISRCTN | ISRCTN wordt niet meer aangevraagd. |
| OMON | NL-OMON39133 |

# Resultaten

**Samenvatting resultaten**
N/A