

# Supporting people with learning disabilities (LD) who are affected by a relative or friend with cancer

<b>Submission date</b> 21/04/2011	<b>Recruitment status</b> No longer recruiting	<input type="checkbox"/> Prospectively registered <input type="checkbox"/> Protocol
<b>Registration date</b> 21/04/2011	<b>Overall study status</b> Completed	<input type="checkbox"/> Statistical analysis plan <input checked="" type="checkbox"/> Results
<b>Last Edited</b> 01/05/2012	<b>Condition category</b> Cancer	<input type="checkbox"/> Individual participant data

## Plain English summary of protocol

Not provided at time of registration

## Contact information

### Type(s)

Scientific

### Contact name

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## Additional identifiers

EudraCT/CTIS number

IRAS number

ClinicalTrials.gov number

Secondary identifying numbers

9463

# Study information

## Scientific Title

### Study objectives

1. To explore the experiences of people with learning disabilities who have a relative or friend with cancer
2. To identify the cancer information and support needs of this group
3. To identify the barriers people with learning disabilities face to receiving adequate information and support when a relative or friend has cancer
4. To make recommendations for
  - 4.1. Practice
  - 4.2. The development of resources
  - 4.3. Future research, to ensure that people with learning disabilities are adequately supported when a relative or friend has cancer

### Ethics approval required

Old ethics approval format

### Ethics approval(s)

Medical Research Ethics Committee on 10/06/2009 Ref: 09/H0716/37

### Study design

Multi-Centre Non-randomised Interventional Process of Care

### Primary study design

Interventional

### Secondary study design

Non randomised controlled trial

### Study setting(s)

Other

### Study type(s)

Quality of life

### Participant information sheet

Not available in web format, please use the contact details below to request a patient information sheet

### Health condition(s) or problem(s) studied

All cancers

### Interventions

1. Four focus groups of 6 participants
2. Each focus group will meet 4 times:
  - 2.1. Getting to know you: introducing the study, and beginning to tell your story
  - 2.2. What was good/difficult about what other people did (or didnt do) to help you understand

and manage?

2.3. What could have been done better? What are your recommendations?

2.4. Nominal Group Technique will be used to elicit the most important recommendation

3. The focus groups will be conducted by two researchers (one to moderate the discussion, and one to make notes) and two co-researchers with learning disabilities who will support the lead researcher

4. The data will be analysed using content analysis supported by Nvivo software. All three researchers (including the co-researcher with learning disabilities) will analyse the data

## **Intervention Type**

Other

## **Phase**

Not Applicable

## **Primary outcome measure**

1. Participants' views on supportive measures, obtained through Nominal Group Technique at the session 4 of each focus group

2. Final qualitative analysis of participants' views on completion of final focus group (April/May 2011)

## **Secondary outcome measures**

Not provided at time of registration

## **Overall study start date**

01/02/2010

## **Completion date**

02/02/2011

# **Eligibility**

## **Key inclusion criteria**

1. People with learning disabilities who have some verbal skills
2. Age 18 or over
3. Have lived with a relative/friend with cancer in the past 5 years
4. Target Gender: Male & Female
5. Lower Age Limit 18 years

## **Participant type(s)**

Patient

## **Age group**

Adult

## **Lower age limit**

18 Years

## **Sex**

Both

**Target number of participants**

Planned Sample Size: 24; UK Sample Size: 24

**Key exclusion criteria**

Recent bereavement (less than 6 months)

**Date of first enrolment**

01/02/2010

**Date of final enrolment**

02/02/2011

## **Locations**

**Countries of recruitment**

England

United Kingdom

**Study participating centre**

St George's University of London

London

United Kingdom

SW17 0RE

## **Sponsor information**

**Organisation**

St George's University of London (UK)

**Sponsor details**

Division of Mental Health, Cranmer Terrace

London

England

United Kingdom

SW17 0RE

**Sponsor type**

University/education

**ROR**

<https://ror.org/040f08y74>

# Funder(s)

## Funder type

Charity

## Funder Name

Macmillan Cancer Support

# Results and Publications

## Publication and dissemination plan

Not provided at time of registration

## Intention to publish date

## 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?
<a href="#">Results article</a>	qualitative study results	01/12/2012		Yes	No