

# 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

### Protocol serial number

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

**Study type(s)**

Quality of life

**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(s)**

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)

**Key secondary outcome(s)**

Not provided at time of registration

**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

**Healthy volunteers allowed**

No

**Age group**

Adult

**Lower age limit**

18 years

**Sex**

All

**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**

United Kingdom

England

**Study participating centre**  
**St George's University of London**  
London  
United Kingdom  
SW17 0RE

## Sponsor information

**Organisation**  
St George's University of London (UK)

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

## Funder(s)

**Funder type**  
Charity

**Funder Name**  
Macmillan Cancer Support

## 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?
<a href="#">Results article</a>	qualitative study results	01/12/2012		Yes	No
<a href="#">Participant information sheet</a>	Participant information sheet	11/11/2025	11/11/2025	No	Yes