

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

Submission date 21/04/2011	Recruitment status No longer recruiting	<input type="checkbox"/> Prospectively registered
		<input type="checkbox"/> Protocol
Registration date 21/04/2011	Overall study status Completed	<input type="checkbox"/> Statistical analysis plan
		<input checked="" type="checkbox"/> Results
Last Edited 01/05/2012	Condition category 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?
Results article	qualitative study results	01/12/2012		Yes	No