

Reducing barriers and improving access to support for young carers (REBIAS-YC)

Submission date 11/12/2020	Recruitment status No longer recruiting	<input checked="" type="checkbox"/> Prospectively registered <input type="checkbox"/> Protocol
Registration date 15/12/2020	Overall study status Completed	<input type="checkbox"/> Statistical analysis plan <input checked="" type="checkbox"/> Results
Last Edited 27/09/2024	Condition category Other	<input type="checkbox"/> Individual participant data

Plain English summary of protocol

Background and study aims

The study aims to improve support and quality of life for the many children and young people in England who provide support to family members or friends who are disabled, have mental or physical ill health, or misuse drugs or alcohol. These are sometimes called young or young adult carers. In our study, we will focus on the experiences of children and young people aged 9-25. Research shows that some young carers and the people they care for do not receive all the services and support that they need. Some young carers may face additional difficulties. Research is needed to understand why this is the case and ensure support is given to those most in need of it. We want this study to help answer two main questions. Firstly, what are the difficulties faced by young carers and the people they support in seeking, accessing, and receiving the right type of support at the right times? Secondly, what services and support do they find helpful, what support would they like, and what needs would it meet?

Who can participate?

Children and young people aged between 9 and 25 providing unpaid care in England and the people they support

What does the study involve?

Focus groups and in-depth interviews.

What are the possible risk and benefits of participating?

The possible risks are the time taken to read the Information Sheet and take part in a focus group or interview and that the questions we ask about what services and support people get or do not get, may feel uncomfortable or upsetting to some people. Such questions will be kept to a minimum and participant do not need to answer any questions they do not wish to and can withdraw from the interview or focus group at any time without giving a reason. Support measures are in place for people taking part, as needed. The possible benefits to taking part are both direct and indirect. There may be benefits to sharing experiences and hearing about other people's experiences in a supportive environment. There may also be a benefit from contributing to research that may lead to improved support for young carers and the people they support. That support may help young carers in the longer term.

Where is the study run from?

Care Policy and Evaluation Centre, London School of Economics and Political Science (LSE) (UK)

When is the study starting and how long is it expected to run for?

January 2021 to December 2022

Who is funding the study?

National Institute for Health Research (NIHR) (UK)

Who is the main contact?

Nicola Brimblecombe

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Contact information

Type(s)

Scientific

Contact name

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Additional identifiers

EudraCT/CTIS number

Nil known

IRAS number

ClinicalTrials.gov number

Nil known

Secondary identifying numbers

NIHR129645

Study information

Scientific Title

What are the barriers to young carers accessing carer support services and/or services for the recipient of care, and what interventions and support services are acceptable to these groups and the persons they look after?

Acronym

REBIAS-YC

Study objectives

The aims and objectives are to explore the following questions:

1. What components, features and/or types of interventions, services and other support are, or would be, acceptable to young carers and the people they support?
2. What additional support is perceived as needed?
3. What are the barriers experienced by young carers in seeking and accessing services for themselves or the person they support?
4. What are the barriers and facilitators for practitioners in providing support and services perceived as acceptable by young carers and the people they support?
5. What are the estimated costs of providing support and services perceived as acceptable? How do these compare to the estimated economic implications of not meeting those needs?

Ethics approval required

Old ethics approval format

Ethics approval(s)

Approved 11/05/2021, LSE Ethics Committee (London School of Economics and Political Science, Houghton Street, London, WC2A 2AE, UK; no telephone number available; l.grove@lse.ac.uk), ref: 1247

Study design

In-depth qualitative study utilising focus groups and in-depth semi-structured interviews

Primary study design

Observational

Secondary study design

Qualitative study

Study setting(s)

Community

Study type(s)

Other

Participant information sheet

Not available in web format, please use contact details to request a participant information sheet.

Health condition(s) or problem(s) studied

Children and young people aged between 9 and 25 providing unpaid care and the people they support

Interventions

Current intervention as of 28/01/2022:

This is an in-depth qualitative study that aims to ask questions about services and support received and needed, and barriers to accessing and receiving support.

A total of 6-8 focus groups will be held in each of four localities in England, with approximately 8 participants per group. Focus groups will be co-facilitated by project workers in the local areas and will aim to discuss participants' experiences with services, features of services and support needed, and barriers to seeking support. One-to-one in-depth semi-structured interviews (approx. 18 in total) will be conducted where participants prefer this alternative. Data will be collected at one point in time with no follow up.

Previous intervention:

This is an in-depth qualitative study that aims to ask questions about services and support received and needed, and barriers to accessing and receiving support.

A total of 6-8 focus groups will be held in each of three localities in England, with approximately 8 participants per group. Focus groups will be co-facilitated by project workers in the local areas and will aim to discuss participants' experiences with services, features of services and support needed, and barriers to seeking support. One-to-one in-depth semi-structured interviews (approx. 18 in total) will be conducted where participants prefer this alternative. Data will be collected at one point in time with no follow up.

'Workshops' refer to practitioner workshops to explore the applicability of the findings to practice. Mention of workshops should be deleted from the current trial registration. I apologise for this error.

Intervention Type

Other

Primary outcome measure

Difficulties in seeking, accessing, and receiving support measured using focus groups and one-to-one interviews at one point in time analysed using inductive thematic analysis

Secondary outcome measures

There are no secondary outcome measures

Overall study start date

01/03/2019

Completion date

31/12/2022

Eligibility

Key inclusion criteria

Current participant inclusion criteria as of 28/01/2022:

Children and young people aged between 9 and 25 providing unpaid care and the people they support in four specific pre-defined (confidential) localities in England

Previous participant inclusion criteria:

Children and young people aged between 9 and 25 providing unpaid care and the people they support in three specific pre-defined (confidential) localities in England

Participant type(s)

Mixed

Age group

Mixed

Sex

Both

Target number of participants

Up to 144

Total final enrolment

133

Key exclusion criteria

Current participant exclusion criteria as of 28/01/2022:

1. Carers aged 26+ and the people they support
2. Children and young people aged between 9 and 25 providing unpaid care not living in one of the four specific pre-defined (confidential) localities in England

Previous participant exclusion criteria:

1. Carers aged 26+ and the people they support
2. Children and young people aged between 9 and 25 providing unpaid care not living in one of the three specific pre-defined (confidential) localities in England

Date of first enrolment

01/05/2021

Date of final enrolment

01/05/2022

Locations

Countries of recruitment

England

United Kingdom

Study participating centre

London School of Economics and Political Science
Houghton Street

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Sponsor information

Organisation

London School of Economics and Political Science

Sponsor details

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Sponsor type

University/education

Website

<http://www.lse.ac.uk/home.aspx>

ROR

<https://ror.org/0090zs177>

Funder(s)

Funder type

Government

Funder Name

National Institute for Health Research

Alternative Name(s)

National Institute for Health Research, NIHR Research, NIHRresearch, NIHR - National Institute for Health Research, NIHR (The National Institute for Health and Care Research), NIHR

Funding Body Type

Government organisation

Funding Body Subtype

National government

Location

United Kingdom

Results and Publications

Publication and dissemination plan

Planned publication of papers in peer-reviewed academic journals; articles in practitioner journals; presentations at academic and practitioner conferences; findings workshop; policy /briefing papers.

Intention to publish date

01/09/2023

Individual participant data (IPD) sharing plan

The datasets generated during and/or analysed during the current study are not expected to be made available as data generated are not suitable for sharing beyond that contained within the project outputs because of privacy, safety and data protection

IPD sharing plan summary

Not expected to be made available

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Results article		01/09/2024	27/09/2024	Yes	No