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

**Submission date**
11/12/2020

**Recruitment status**
No longer recruiting

**Registration date**
15/12/2020

**Overall study status**
Completed

**Last Edited**
27/09/2024

**Condition category**
Other

[X] Prospectively registered
[_] Protocol
[_] Statistical analysis plan
[X] Results
[_] 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
n.s.brimblecombe@lse.ac.uk

# Contact information

### Type(s)
Scientific

### Contact name
Ms Nicola Brimblecombe

### ORCID ID
https://orcid.org/0000-0002-6147-5726

### Contact details
London School of Economics and Political Science
Houghton Street
London
United Kingdom
WC2A 2AE
+44 (0)207 955 6376
n.s.brimblecombe@lse.ac.uk

# Additional identifiers

### National Institute for Health and Care Research (NIHR)
129645

# 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

## Primary study design
Observational

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

## Study type(s)
Other

## 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(s)
Difficulties in seeking, accessing, and receiving support measured using focus groups and one-to-one interviews at one point in time analysed using inducive thematic analysis

### Key secondary outcome(s)
There are no secondary outcome measures

### 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

### Healthy volunteers allowed
No

### Age group
Mixed

### Sex
All

### 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
United Kingdom

England

### Study participating centre
**London School of Economics and Political Science**
Houghton Street
London
United Kingdom
WC2A 2AE

## Sponsor information

### Organisation
London School of Economics and Political Science

### 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

### 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 |