

Encouraging healthy weight for adults living with learning disabilities: supporting the role of carers

Participant Information Sheet (managers & commissioners)

Invitation and brief summary

We would like to invite you to take part in our research study.

The study aims to improve the support available to people who care for adults with Learning Disabilities who would benefit from losing weight. We are interested in the views of people who manage and commission these services, as well as those of formal and informal carers who may benefit from the intervention we develop.

Taking part would mean meeting for a chat with a researcher (Karen Coulman) who will ask about your experiences of managing / commissioning services in this area and your views about existing information and training resources for carers. The research interview would be held on-line and will take approximately 45 minutes of your time.

Before you decide whether or not to take part, we would like you to read the following information to understand why the research is being carried out, and what taking part would involve. Please contact us if anything is unclear, or if there is anything else you would like to know before deciding whether or not to take part.

What is the purpose of the study?

The purpose of this study is to develop a new healthy living training intervention for paid and unpaid carers who support adults with learning disabilities. We want to know about some of the challenges involved in managing and commissioning services in this area, as well as what aspects of current training interventions you think are helpful or could be improved. We want to know about your experiences of working in this area, and any factors that you think are important for us to know before we design and roll out our new intervention. We are also interested in your broader views about healthy weight management for this group of adults, and what areas you think are important to research next.

Why have I been invited to participate?

You have been asked to participate due to your involvement in the management or commissioning of services for adults with learning disabilities and / or weight management needs. 10-15 professionals will be invited to participate in the research, alongside with 10-15 carers.

Do I have to take part?

No. If you do decide to take part you will be asked to sign consent form to confirm you have read this information and are willing to take part. If you decide to take part you are still free to withdraw at any time and without giving a reason. You can withdraw your data after the interview by emailing the main researcher or project lead at any time. However, after 28 days we cannot guarantee that your contributions have not impacted on ongoing analytic models.

What will taking part involve?

If you decide to take part, the main researcher (Karen Coulman, contact details below) will contact you to arrange a time to meet for a research interview, which will last about 45 minutes and will take place on-line. You will be asked to sign a consent form in advance and return it over email – a typed signature is fine, and we will ask you at the start of the interview to confirm that this was you. If you agree, we would like to audio record the interview for research purposes. The interview will then be transcribed (converted to text) by a professional transcribing company who have a confidentiality agreement with the University of Bristol. At this stage your names and other identifying information will be removed.

What are the possible risks and benefits of taking part?

The only disadvantage to you is giving up some of your valuable time to participate in the research interview, and there are no direct benefits to participation in the research. However, I hope participation in the research will be enjoyable and rewarding and that we have an opportunity to talk together about the best ways to improve support for carers of adults with learning disabilities who would benefit from losing weight.

Will my taking part in this study be kept confidential?

Yes. We will not tell anyone if you decide to take part in this research, and we will not tell anyone what you say during research interviews. An anonymous code will be applied to the interview recording and subsequent transcript, and all personally identifiable data will be kept separately.

What will happen to my personal data?

Your name and address will be kept separately from the anonymised interview data on secure, password protected University computers and only accessed by Drs Karen Coulman (main researcher) and Amanda Owen Smith (study lead). Any identifiable information about you will be destroyed three months after the study has ended.

Who else can access my data in the future?

We would like to add the anonymised data generated from this research to a databank that other researchers can access in the future. This would not include your personal data or information that could link the study to you. Data could only be accessed with the permission of a formal data access committee who will make sure it is only used for valid and worthwhile purposes. However, you do not have to agree to this, and you can leave this box unchecked on the consent form without giving a reason. Your participation in the research will not be affected.

How will the results of the project be used?

The results of the study will be used to design and share a new healthy weight training intervention for carers of adults with learning disabilities. This intervention will be available on-line and face-to-face and will be free to use. It will be uploaded to NHS England's E-learning for Health training platform (<https://www.e-lfh.org.uk>) to make sure as many people as possible can benefit. Broader findings from the study will be shared with public sector commissioners, carer support groups, and academics through conference presentations and publications in academic journals. We may choose to use some direct quotes in reporting the results, but there will never be names attached to these, and we will not tell anyone who took part.

Who is organising and funding the research?

The research has been funded by Health Education England (now NHS England) and is jointly managed by the University of Bristol and the UK Government's Office for Health Improvement and Disparities. The study has been reviewed by the University of Bristol Health Sciences Faculty Research Ethics Committee (FREC) to ensure it meets ethical standards with regards to participant safety and confidentiality.

What if there is a problem?

We hope there will not be any problems with the conduct of the study. However, if you have any concerns, you should ask to speak to the main researcher (Karen Coulman – contact details below), or the Chief Investigator (Amanda Owen-Smith) who will do their best to

answer your questions. If you remain unhappy and wish to seek further advice, please contact Research-Governance@bristol.ac.uk.

Thank you for taking the time to read this information, and please do not hesitate to get in touch if you would like any further information.

Contact details:

Karen Coulman, Bristol Medical School, University of Bristol
1-5 Whiteladies Road, Bristol BS8 1NU
Karen.coulman@bristol.ac.uk 0117 455 7944

GDPR statement

The University of Bristol is the sponsor for this project and will act as the data controller for this project. This means that we are responsible for looking after your information and using it properly.

What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have if you withdraw after data analysis has already started. This will be one month after you complete your interview.

Where can you find out more about how your information is used?

You can find out more about how we use your information

- By contacting the chief investigator for this project Dr Amanda Owen Smith a.owen-smith@bris.ac.uk or Dr Karen Coulman karen.coulman@bristol.ac.uk
- By sending an email to the University of Bristol Data Protection Officer Henry Stuart: data-protection@bristol.ac.uk, or by ringing the data protection officer on: 0117 39 41824

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO).