

## PARTICIPANT INFORMATION SHEET

### Relational accommodation in Body Dysmorphic Disorder

**Title of Study 1:** Caregivers Experiences of BDD

**Title of Study 2:** Caregivers' Appraisal of The Family Accommodation Scale for BDD

**University of Surrey Ref:** FHMS 22-23 236 EGA

**PLEASE KEEP A COPY OF THIS INFORMATION SHEET FOR YOUR RECORDS**

### Section: Taking Part

#### Invitation Paragraph

Nicole Bebbington and Deanna Fallah, Trainee Clinical Psychologists at the University of Surrey are undertaking a piece of research as part of their doctoral thesis both on the experience of living with an individual with Body Dysmorphic Disorder (BDD) or anxiety about their appearance. We would like to invite you to participate in either one or both research projects. You should only participate if you want to; choosing not to take part in one or both will not disadvantage you in any way. Before you decide whether you want to take part in one or both, it is important for you to understand why the research is being done and what your participation will involve. If you have any questions, you can contact us using the contact details at the end of this information sheet.

#### What is the purpose of the study?

There is little research inviting caregivers to share their experience of supporting someone with BDD or appearance anxiety. We are carrying out **two** research studies aiming to understand more about the experience of caring for someone with BDD / appearance anxiety. We will specifically be looking at experiences of **relational accommodation**, which is the term used to describe when caregivers change their behaviour in response to the mental health difficulties of the person they are caring for, to reduce their distress. We hope that gaining a better understand of this might improve treatment for appearance anxiety.

#### **Study 1:**

The aim of study 1 is to determine whether relational accommodation presents in relatives and significant others living with someone with appearance anxiety. We are specifically interested in the various ways that family members and significant others respond to appearance anxiety in their relatives/partner, and the impact this might have on them.

This will involve taking part in a 90-minute interview where participants will be asked to share their lived experience of relational accommodation.

#### **Study 2:**

The aim of study 2 is to investigate if a newly developed self-report questionnaire captures relatives and significant others lived experience of supporting someone with BDD or appearance anxiety. We are specifically interested in the extent to which relatives and significant others feel the questions in the questionnaire capture their experience, and any questions that may be missing.

This will involve taking part in a 90-minute interview. The interview will be sectioned into two parts. Part one will ask participants to complete the questionnaire whilst speaking aloud their thoughts and opinions of it. In part two participants will be asked questions about their opinion of the questionnaire.

### **Who is responsible for this study?**

These studies are the responsibility of Deanna Fallah (Study 1) and Nicole Bebbington (Study 2) at the University of Surrey.

### **Why have I been invited to take part?**

We are inviting you and other similar potential participants to take part because of your experiences of living with someone with BDD or significant appearance anxiety.

To be eligible to take part in one or both studies, you must be:

- Over 18 years old
- A family member/significant other supporting an adult (18+ years) with Body Dysmorphic Disorder or appearance anxiety.
- Cohabiting for a minimum of six months with an adult with Body Dysmorphic Disorder or appearance anxiety.
- Be able to take part in either one or two 90-minute interviews via Microsoft Teams.

You are not eligible to take part in the study if:

- Verbal and written English ability that would prevent you from being able to take part in an interview.

### **Do I have to take part?**

Participation in one or both studies is voluntary, and you do not have to take part. We will describe both studies in this information sheet and will give you 14 days to read this, so you can decide whether you wish to take part. If you do not respond to the forms within this time, we will make follow up contact with you. Please contact us if there is anything that is not clear, or if you have any questions, or need more information.

### **What will happen to me if I decide to take part?**

If you decide to take part, you will be given this information sheet to keep and will be asked to sign a consent form to confirm your agreement to participate in either or both studies. You will be given a copy of this consent form to keep.

The below outlines step-by-step the process following your consent to participate:

- For each study that you consent to participate in, the researcher will contact you via email or telephone to offer an initial 10-minute video call on Microsoft Teams, to answer any questions that you may have and to discuss next steps.
- For each study that you consent to participate in, you will be invited to take part in a 90-minute interview by the researcher. If you choose to participate in both interviews, they will be arranged and conducted separately. These will take place at a time convenient for you. Interviews will be held online via Microsoft Teams.
- Both studies will start with a 10-minute introduction where we will discuss timings, be able to answer any further questions and agree on breaks.
- On completion of the interview, participants will be given a study debrief and reimbursed for their time.
- Participation in either study will be roughly 90 minutes each.

We will collect the following personal information including contact details, ethnic origin, gender, age and sexual orientation to support answering the research questions and guide future research.

You will be assigned a unique participant ID number after expressing interest in taking part in the study. Audio/visual recordings of the interview will be taken and transcribed verbatim. Transcripts will be identified only by this participant ID number and will not be used or made available for any purposes other than the research project. The recordings and the transcripts will be held and stored securely on a University of Surrey secure server. Only the research team and responsible members of the University may be given access to this.

We will destroy audio/visual recordings once they have been transcribed.

### **What happens if I do not want to take part or if I change my mind?**

You are free to withdraw from either study at any time, without giving a reason. If you decide not to take part in either study prior to the interview, you can email the researcher to withdraw your consent to participate. Once you have attended the interview you will be reimbursed for your time and withdrawal after this point will not impact on this. Should you wish to withdraw your data following the interview, you can email the researcher within four weeks of the interview requesting to withdraw your data and all research and personal information will be deleted.

### **What happens to my data if I want to withdraw?**

If you wish to withdraw your data from the study, you will need to email your participant ID to the researcher and request your data is deleted. You will be able to withdraw your data you have provided up to 4 weeks after each study interview. Following this time, as the interview will be transcribed and fully anonymised, it will not be possible to remove the information you have provided. We will delete all personal information provided by you.

### **What are the possible benefits in taking part?**

The information we will get from the study will inform and potentially improve existing treatment options for Body Dysmorphic Disorder.

You will receive reimbursement for your participation, in the form of shopping vouchers. This will be £20 for each study completed.

### **Are there any potential risks involved?**

A possible disadvantage to taking part in the study is that some matters touched on during the interview may be distressing for you. To minimise any distress, you can take breaks or terminate the interview at any time. The researchers will also signpost you to sources of support at the end of the interview.

### **How is the project being funded?**

This research is a student project as part of the researchers' doctoral thesis at the University of Surrey.

### **Will my participation be kept confidential?**

We are responsible for making sure your participation is kept confidential and any data is kept secure and used only in the way described in this information sheet.

Your information may be reviewed for monitoring and audit purposes, by the University of Surrey and/or regulators who will treat your data in confidence.

All the information that we collect about you during the research will be kept strictly confidential and only accessed by members of the research team or responsible members of the University for auditing and/or monitoring purposes. You will not be able to be identified in any ensuing reports or publications.

We advise you that participants' confidentiality will always be respected, unless there are compelling and legitimate reasons for this to be breached. We have a duty of care to report to the relevant authorities any possible harm or danger to participants or others.

### **Will my data be shared or used in future research studies?**

At the end of this study, with your consent, your data will be held securely in the University of Surrey Data Repository. This may be used in other research projects. We would like your permission to use anonymised data in future research studies, and to share data with other researchers (e.g. in online databases). All personal information that could identify you will be removed or changed before information is shared with other researchers or results are made public.

Information may be subject to review by responsible individuals from the University of Surrey and/or regulators for monitoring and audit purposes.

### **What will happen to the results of the study?**

We will publish the results from the research study in peer reviewed scientific journals and present them at conferences. Any published findings or quotations will use pseudonyms and will maintain your confidentiality and anonymity. You will not be personally identified in any reports or publications.

You can contact the study team to find out the results of the research on completion of the research.

### **Who has reviewed this study?**

This study was reviewed and given a favourable ethical opinion by the University of Surrey Ethics Committee - FHMS 22-23 236 EGA.

## Section: Your personal data

### **What is personal data?**

'Personal Data' means any information that identifies you as an individual. We will be collecting and using some of your personal data that is relevant to completing the study and this section describes what that means.

The information that we will collect will include your name and contact details which is regarded as 'personal data' and age, ethnic origin, sexual orientation and gender, which is regarded as a 'special category personal data'. We will use this information as explained in the 'What is the purpose of the study' section above.

### **Who is handling my personal data?**

The University of Surrey, who has the legal responsibility for managing the personal data in this study, will act as the 'Data Controller' for this study. The research team will process your personal data on behalf of the controller and is responsible for looking after your information and using it properly.

We will be using an approved third-party online data collection tool to collect information about you before you take part in the interview. Once this data is collected, we will move the data to university storage and delete it from the tool at the end of the project. Interviews will be transcribed using Microsoft Teams and transferred immediately following the interview to secure university digital storage.

### **What will happen to my personal data?**

As a publicly funded organisation, we must only use **identifiable personal** information from people who have agreed to take part in research and process this data fairly and lawfully. The University of Surrey processes personal data for the purposes of carrying out research in the **public interest** and special category data is processed on an additional condition necessary for **research purposes**. This means that when you agree to take part in this research study, we will use and look after your data in the ways needed to achieve the outcomes of the study.

With consent, your personal data will be held and processed in the strictest confidence, and in accordance with current data protection regulations. When acting as the data controller, the

University will keep identifiable information about you for 10 years after the study has finished after which time any identifiers will be removed from the aggregated research data.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways or the research to be reliable and accurate. If you decide to withdraw from the study, we may not be able to withdraw your data. We will keep and use the minimum amount of your personally identifiable information that we have already collected to complete the study.

If you wish to complain about how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter ([dataprotection@surrey.ac.uk](mailto:dataprotection@surrey.ac.uk)). 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 contact the Information Commissioner's Office (ICO) (<https://ico.org.uk/>).

You can find out more about how we use your information <https://www.surrey.ac.uk/information-management/data-protection> and/or by contacting [dataprotection@surrey.ac.uk](mailto:dataprotection@surrey.ac.uk).

## Section: Further information

### **What if you have a query or something goes wrong?**

If you are unsure about something you can contact the research team for further advice using the contact details at the bottom of this information sheet.

However, if your query has not been handled to your satisfaction, or if you are unhappy and wish to make a formal complaint to someone independent of the research team, then please contact:

Research Integrity and Governance Office (RIGO)  
Research and Innovation Services  
University of Surrey  
Senate House, Guildford, Surrey, GU2 7XH  
Email: [rigo@surrey.ac.uk](mailto:rigo@surrey.ac.uk)

The University has in place the relevant insurance policies which apply to this study. If you wish to complain or have concerns about how you have been treated during this study, then you should follow the instructions given above.

### **Who should I contact for further information?**

If you, or your family member/significant other with BDD have any questions or require more information about this study, please contact the research team using the following contact details:

**Deanna Fallah (Study 1)**  
**Trainee Clinical Psychologist**  
School of Psychology, Senate House, Guildford, Surrey, GU2 7XH  
Email: [d.fallah@surrey.ac.uk](mailto:d.fallah@surrey.ac.uk)

**Nicole Bebbington (Study 2)**  
**Trainee Clinical Psychologist**

School of Psychology, University of Surrey, Guildford, Surrey, GU2 7XH  
Email: [n.bebbington@surrey.ac.uk](mailto:n.bebbington@surrey.ac.uk)

**Dr Lucy Hale**  
**Senior Lecturer and Clinical Psychologist**

School of Psychology, University of Surrey, Guildford, Surrey, GU2 7XH  
Email: [l.hale@surrey.ac.uk](mailto:l.hale@surrey.ac.uk)

**Dr Hannah Frith**  
**Associate Professor**

School of Psychology, University of Surrey, Guildford, Surrey, GU2 7XH  
Email: [h.frith@surrey.ac.uk](mailto:h.frith@surrey.ac.uk)

### **Sources of support**

If you feel distressed or are concerned and require support, please contact one of the suggested avenues for support below.

The first point of contact we would recommend is to arrange an appointment with your registered GP.

Samaritans provide emotional support to anyone in emotional distress or struggling to cope and they can be contacted on 116 123 24 hours a day, 365 days a year.

If you feel worried about your immediate safety, please call 999.

For specific support related to Body Dysmorphic Disorder, there are national support services that you can reach out to including:

**Body Dysmorphic Disorder Foundation**

[bddfoundation.org](http://bddfoundation.org)

Support and information for people affected by body dysmorphic disorder.

**British Association for Behavioural and Cognitive Psychotherapies (BABCP)**

[babcp.com](http://babcp.com)

Information about cognitive behavioural therapy and related treatments, including details of accredited therapists.

**Improving Access to Psychological Therapies (IAPT)**

[nhs.uk/service-search/find-a-psychological-therapies-service](https://nhs.uk/service-search/find-a-psychological-therapies-service)

Information about local NHS therapy and counselling services, which you can often self-refer to (England only).

**National Institute for Health and Care Excellence (NICE)**

[nice.org.uk](http://nice.org.uk)

Produces guidelines on best practice in healthcare.

**NHS Services Finder**

[nhs.uk/service-search](https://nhs.uk/service-search) (England)  
[111.wales.nhs.uk/localservices](https://111.wales.nhs.uk/localservices) (Wales)  
Searchable database of NHS services.

**OCD Action**

0300 636 5478

[ocdaction.org.uk](https://ocdaction.org.uk)

Information and support for people affected by OCD and hoarding, including online forums and local support groups.

**OCD-UK**

01332 588 112

[ocduk.org](https://ocduk.org)

Charity run by and for people with OCD.

**Thank you for reading this information sheet and for considering taking part in this research.**