

Centre for Appearance Research
Faculty of Health & Applied Sciences
University of the West of England
Frenchay
Bristol, BS16 1QY



'Visible Difference, Intimacy and Romantic Intimate Relationships'
(the 'Study')

PARTICIPANT INFORMATION SHEET

You are being invited to take part in a research study. Before you decide whether you wish to take part, it is important for you to know why the research is being done and what it will involve. Please read the information below carefully. Ask us if anything is unclear or if you would like to know more.

1. *Why is this research taking place?*

Many people live with visible differences, by which we mean any appearance altering or disfiguring condition. These conditions have many causes and the resulting alteration in appearance can impact on some people's quality of life. In order to provide appropriate support, it is important for doctors, nurses, psychologists and researchers to understand the nature and extent of this impact.

At the moment relatively little is known about how visible differences may affect close intimate relationships and what proportion of people with a visible difference experience difficulties in this area. We are therefore asking people to complete a series of questionnaires related to visible difference, intimacy and sexual activity, being evaluated by others and their related thoughts, feelings, experiences and behaviours. These include some questionnaires that have previously been used and one that we have developed based upon interviews that we have conducted with people who have a visible difference.

The results of the Study will be published to improve healthcare and research professionals' understanding of the area. We will also use the results to test, refine and shorten the questionnaire that we have developed so that we know which questions are most useful for researchers and clinicians so that they may measure the impact of visible differences upon intimate relationships and provide suitable support.

As we are refining the questions that we have developed you may feel that some of them are similar to one another. We are aware of this and it is deliberate so please do not consider any repetition to be problematic.

2. *Why have I been chosen to participate?*

You are being asked to participate if you are eighteen years old or older, have a visible difference or have had a visible difference in the past. We may also seek some input from people who are eighteen years old or older do not have a visible difference. If either case, if you have been diagnosed with any mental health condition that is not being controlled by treatment and which has a significant impact upon the activities of daily living then we would ask that you refrain from taking part.

3. What will this research involve?

If you would like to take part then you will be asked to agree to a consent form that covers your participation, to provide some demographic information and then to complete a series of on-line questionnaires relating to visible difference, intimacy and sexual activity, being evaluated by others and their related thoughts, feelings, experiences and behaviours. We think that this should take about 25-30 minutes in total.

If you would prefer to participate in the Study using printed materials and/or you require someone to read the questions and responses out to you then please contact the researcher, Nick Sharratt (contact details below), and Nick can help arrange this for you.

4. Do I have to take part?

Your participation is entirely voluntary so it is up to you to decide whether or not to take part. If you decide to take part then you can change your mind at any time before or during your participation. If you do change your mind, you do not have to give any reason and none of the research team will question your decision in any way. If you do take part but do not want to answer any question then this is also your decision.

If you complete (in whole or in part) the questionnaires but decide that you would not like it to be used, please let the researcher know within four weeks of completing (in whole or in part) the questionnaire. If you do this then no further use will be made of your information.

5. What are the possible benefits of taking part?

It is unlikely that your participation will confer any immediate or direct benefit on you. We hope that the research will increase healthcare professionals' and researchers' understanding of people's experiences of visible difference and intimacy. We also hope the shortened version of the questionnaire we have developed will be used by researchers and clinicians to assess the impact of visible differences upon intimate relationships and provide appropriate support should this be necessary. Your participation will help us achieve these aims.

As a small thank you for taking part and as the completion of the study will take a little time, we are able to provide each participant that completes the study with a £10 Amazon voucher code. To receive this you need to progress to the end of the questionnaire and provide a phone number or email address so that the researcher can contact you. Please remember that as we are not asking for your name the researcher will not know your name when they do contact you. The researcher will try to contact you and will leave a message if you provide a phone number and it goes to answerphone or send an email if you provide an email address. This message will contain the code. We cannot accept any responsibility if the details you provide are inaccurate or you are unable to retrieve your code.

Please note that only one voucher code can be provided per participant and you should not participate more than once. Voucher codes will not be provided if the questionnaires are not completed properly and attentively.

6. What are the possible risks of taking part?

We are always required to tell you about any possible risks of taking part in research. In this instance, however, we are not aware of there being any significant risks to you. The only risk we

anticipate is that you may find answering the questions upsetting in some way. If you do, you can take a break or withdraw from the Study. Of course, you may also take a break or withdraw for any other reason.

It is important that you are aware that this is a research study and the research team cannot offer any counselling or therapy to you. If you do find the experience upsetting and would like to talk to someone about how you're feeling, lists of relevant organisations that may be able to assist may be found at the web-pages of either: [Changing Faces](#) or [The Centre For Appearance Research](#) (both hyperlinked)

7. Who is running and funding the research?

The Study is funded by the University of the West of England and is being conducted by researchers in the Centre for Appearance Research which is a research centre within the University of the West of England. Details of the main researchers involved are provided below.

8. Who has reviewed the Study?

The Study has been reviewed and approved by an ethics committee from the Faculty of Health and Applied Sciences from the University of the West of England.

9. Will my responses be shown to anyone?

The information you provide to us will not normally be shown to anyone outside of the research team and its professional collaborators and/or service providers involved in or with the Study and will be used only for research purposes. Your responses (this includes your demographic details and your questionnaire responses) will, however, be pooled with those of other people and used as part of the results of the Study.

For this research we do not need to know your name and so do not ask you to provide it. You will only need to provide contact details if you wish to receive the thank you gift (described below).

10. What will happen to the results of the Study?

The results and the information you provide will be shared with other researchers and healthcare professionals, presented at talks and conferences, published (including in reports and journals) and used as part of a PhD thesis. We will not include your name or any information from which you can be identified in any summary of the results, publications, talks or conference papers.

11. Data Protection Notice

The personal information collected for the Study will be processed by the University of the West of England in accordance with the terms and conditions of the 1998 Data Protection Act. We will hold your data securely and not make it available to any third party unless permitted or required to do so by law. Your personal information will be used and processed as follows:

- a) The data you provide will be collected by the University of the West of England for the purposes of academic research and shall be stored, used, analysed, disseminated and published for these purposes

- b) No dissemination or publication of the data you provide shall identify you individually. Your data will be disseminated and published in aggregate form, combined with other study participants
- c) Your individual data will be used only by the researchers involved in the Study and by third parties who are their professional collaborators and/or service providers and in each case only for the purposes of the Study, in a manner consistent with the data Protection Act 1998 and in an anonymous form so that you shall not be individually identified any third party or professional collaborator
- d) The data you provide will be stored securely by the University of the West of England on its secure servers and/or in a locked cabinet and shall be kept for a period of 5 years. After this time it will be permanently destroyed or deleted
- e) If you participate via an online survey the data you provide will also be held by the survey provider (Qualtrics) as a Data Processor. The University of the West of England has terms in place with this Data Processor that require such data be held by it in a manner consistent with the Data Protection Act 1998
- f) If you wish to receive the Amazon vouchers then you must provide an email address or phone number with which you can be contacted. This information will be subject to this Data Protection Notice but will be used only by the researchers and only to contact you in the event that you are successful.

The University Data Controller is William Marshall, Pro-Vice Vice Chancellor, Commercial Director and Corporation Secretary.

12. Contact for further information

If have any questions or require any further information or would like to be sent hard copies of the questionnaires or require any assistance in completing them, please contact Nick Sharratt who is conducting the Study and is a PhD Researcher in the Centre for Appearance Research at the University of the West of England. Nick can be contacted by e-mail: nick.sharratt@uwe.ac.uk or by phone on 0117 328 1891.

If you wish to discuss the Study with anybody else, if you have any complaints connected with the Study or wish to pass any comments to the ethics committee that reviewed the Study, please contact Professor Nichola Rumsey who can be contacted by phone on 0117 328 3989. Professor Rumsey is a co-director of the Centre for Appearance Research at the University of the West of England and is supervising the performance of the Study.

The address of the Centre for Appearance Research is:

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Please feel free to pass this information sheet on to anyone that you know who you think may be interested in participating in the Study.

Thank you for taking the time to read this information sheet and for considering whether you wish to participate