

**Exploring and Measuring the Perceived Impact of Visible Difference upon  
Romantic Relationships  
Volume II (Appendices)**

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West of England, Bristol for the degree of Doctor of Philosophy**

**Faculty of Health and Applied Sciences, University of the West of England**

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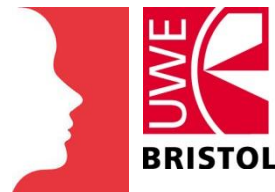
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## **Appendices (A1-F)**

## **Appendix A1: Qualitative Study: Participant Information Sheet**

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



University of the  
West of England

### **‘Exploring Experiences of Visible Difference, Intimacy and 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 and discuss it with others if you wish. Ask us if anything is unclear or if you would like to know more. Please take some time to decide whether you want to take part.

Thank you for reading this.

#### ***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 which include the results of a congenital or genetic condition, an accident, surgery or a medical or health condition, disorder or disease. The resulting alteration in appearance can impact on a person’s quality of life in many ways. 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 very little is known about how visible differences may affect close intimate relationships such as those people have with partners and spouses. We would therefore like to know more and believe that the best way of achieving this is to speak to people who have a visible difference or who have been or are the partner of someone with a visible difference.

The results of the Study will be used in a couple of different ways. We will publish the results with a view to improving healthcare and research professionals’ understanding of the area. We will also use the results to develop a questionnaire style measurement scale so that researchers and clinicians can measure the impact of visible differences upon intimate relationships and provide suitable support.

#### ***Why have I been chosen to participate?***

You are being asked to participate if you are eighteen years old or older and have a visible difference, have had a visible difference in the past or you have been or are the partner of someone with a visible difference. Unfortunately we are only able to speak to people who are able to communicate verbally and fluently in the English language. If you have been

diagnosed with any mental health condition then please speak to the researcher about whether you are eligible participate.

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

You do not have to take part. It is your choice whether you decide to or not. If you do decide to take part then you can change your mind at any time, before, during or after the interview. If you do change your mind, you do not have to give any reason and none of the research team will put you under and pressure or question your decision in any way. If you do take part but do not want to answer any question or talk about any particular experience then this is also your decision.

If you complete the interview but decide at a later date that you would not like it to be used, please let the researcher know. If this happens then no further use will be made of your interview or information, however, if any parts or extracts have already been used in presentations or publications it will not be possible to remove them.

***What will happen to me if I do take part?***

If you indicate that you want to take part and you have not seen the consent form then we will send you a consent form that you should read. Before we begin the interview we will need to collect a signed copy of the consent form from you (this could be a hard copy or an electronic version) or, if that is not possible, ask you to e-mail us attaching the consent form and saying that you provide the consent it requires.

When you contact us we will also arrange a convenient date, time and location for an interview and you may choose whether you wish the interview to be conducted over the phone, in person or through an electronic method of communication such as Skype. The interview will be on a one-to-one basis and involve you and the researcher; there will not be anyone else present.

In the interview we will ask you some questions about your experiences of visible differences and intimacy. We really want to hear about your experiences and what is or has been most important to you so these questions will be used only as a flexible guide. We would expect the interview to take between 30 minutes and one hour. We would also like to record the interview audibly so that we can then transcribe what is said to make sure we accurately capture what you say. These audio recordings will be deleted once we have finished compiling the results of the Study and will be kept securely until this time. Other Study information such as the consent forms and transcripts of the interview will be kept for longer but will be stored securely and eventually deleted.

***What do I have to do if I want to take part?***

If you do want to take part, please contact the researcher, Nick Sharratt (contact details below), who is conducting the Study. You may contact Nick by phone or by e-mail. He will answer any questions that you may have and if you are willing to participate, can arrange a convenient date, time and place for the interview to take place.

You can choose whether you would like the interview to be conducted over the phone, in person or through an electronic method of communication such as Skype. We will make your participation as convenient for you as we can. If the interview is to take place over the phone then we will call you at a pre-agreed time and if it is to be in person then we can travel to a location near you or to your home.

***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 the interview will involve you discussing your experiences of visible differences and intimacy and identifying what are the issues that are important to you. If this is at all upsetting, you can take a break or stop the interview at any time. Of course, you may also take a break or stop the interview for any other reason.

It is important that you are aware that this is a research interview and the researcher is not a therapist or counsellor. If you do find the experience upsetting and would like to talk to someone about how you're feeling, we can provide you with details of organisations that provide support to people with visible differences.

***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 to develop a questionnaire style measurement scale so that in the future researchers and clinicians can 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.

***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. Some anonymous direct quotations may be used in presentations and publications related to the research (please see section 9, below).

You should be aware that for the protection of you and others in some, very limited, circumstances we may need to disclose information about you and any events you describe to the relevant authorities. In such circumstances we cannot assure you of your confidentiality but this will only happen if it is compelled by law or a court order or if you disclose any information that raises a serious concern about your safety, the safety of other persons that may be endangered by your behaviour or the health, safety or welfare of any children or vulnerable adults.

***What will happen to the results of the Study?***

A summary of the results will be sent to everyone who takes part and who has asked to see them. The results and direct quotations from interviews 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. We will use a pseudonym instead of your real name and remove or replace the names of any other people or places you talk about.

If you do participate but would like us to refrain from using direct quotations or discussing any particular event that you talk to us about, please let us know.

***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.

Unfortunately, we are not able to provide any payment or compensation for your time in participating in the Study.

***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.

***Contact for further information***

If you would like to take part in the Study have any questions or require any further information, 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](mailto: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:

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

***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***

## Appendix A2: Qualitative Study: Consent Form

Centre for Appearance Research  
Faculty of Health and Applied Sciences  
University of the West of England  
Frenchay  
Bristol, BS16 1QY  
Tel: 0117 328 2497



University of the  
West of England

### ***'Exploring Experiences of Visible Difference, Intimacy and Intimate Relationships' (the 'Study')***

#### **PARTICIPANT CONSENT FORM**

##### **I confirm that:**

1. I am 18 years of age or over, I have a visible difference, have had a visible difference and/or have been or am the partner of someone with a visible difference
2. I understand that I should not participate if I have a diagnosed mental health condition which is currently uncontrolled by medication or intervention and which has a significant impact upon the activities of daily living. I do not have such a condition
3. I have read the information sheet for the Study (version 1.2a dated 29/07/2015), I understand it and I have had the opportunity to ask the research team any questions that I have
4. I understand that I can withdraw from the Study at any time and without providing any reason for doing so
5. I understand that I may withdraw my data from the study at any time and that no future use will be made of my data after that point. It will, however, not be possible to remove my data from any reports, presentations or publications that have been given or accepted for publication before I ask for my data to be withdrawn
6. I understand that I do not have to answer any question I do not want to answer or discuss anything that I do not want to talk about
7. I understand that taking part in this study will involve me being interviewed about my experiences of visible difference and intimacy
8. I agree that my interview can be audibly recorded, will be transcribed and that an anonymised form of what I say may be used in reports, presentations and publications about the study. This may be in the form of summarised information and/or in the form of direct quotations
9. I understand that my name and the name of any people I mention in my interview will be altered and pseudonyms used whenever the study is referred to in reports, presentations and publications
10. I understand that any information I provide and my interview 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. Beyond such researchers, collaborators and service providers it will not be

shared with or provided to any other person unless required by law or court order or for the safety of me or other persons

11. I understand that any information I provide and my interview data will be stored securely by the University of the West of England and kept for a period of 5 years. After this time it will be permanently destroyed or deleted
12. I understand that this study may form part of a larger project and that if I provide my email address and indicate that I am happy for this to happen I may be contacted by the research team who may provide details of further related studies so that I may consider whether I wish to participate in them

**I agree to all the above and I agree to participate in the Study:**

<hr/>	<hr/>	<hr/>
<b>Participant Name</b>	<b>Signed</b>	<b>Date</b>

In order for your data to be stored securely and so that we can identify it should you wish to withdraw from the study, we need to generate a code. Please provide:

The first two letters of your first name:	
The day of the month on which you were born:	
The first two letters of the name of your first school:	

If you would like to receive information about the general findings of this study by e-mail or post, please provide your e-mail or postal address here:

-----

If you would like to receive information about further research related to this study by e-mail or post, please provide your e-mail or postal address here (or if you have already provided it above, please just indicate your assent by ticking the space or writing 'yes'):

-----

The following part will be completed by the researcher:		
<hr/>	<hr/>	<hr/>
Researcher	Signature	Date

Date of interview

## **Appendix A3: Qualitative Study: Interview Guide**

### **Background / context / appearance generally**

Could you tell me a little about the nature of your visible difference?

How important do you think appearance is in general, does it matter what we look like?

How do you feel about your own appearance?

Speaking generally, would you be able to describe any impact that your appearance has had upon your day to day life?

Could you tell me about any changes over time in how you feel about your appearance and any impact it has on your life?

### **Intimate / Romantic Relationships**

Could you say something about any experiences you have of very close, intimate relationships?

Are there any ways in which appearance is important to intimate/romantic relationships?

Would you be able to describe any ways in which your appearance has impacted upon these relationships or this aspect of your life?

What do you think are the important factors in explaining why your appearance has affected you in this way?

What would it take to reduce or remove (or, if positive impact, sustain) this impact?

Could you say anything about whether you have engaged in any specific behaviours or taken any action to reduce or alter any such impact upon your intimate life?

Could you describe the behaviour of your partners or potential partners in connection with your appearance?

How do you feel your partners or potential partners feel or felt about your appearance?

How do you imagine your intimate life would be different if you did not have your visible difference?

How do you feel about the future of your intimate relationships?

**Appendix A4: Qualitative Study: University Research Ethics Committee:  
Application for Ethical Review of Research Involving Human Participants**



**University Research Ethics Committee**

**APPLICATION FOR ETHICAL REVIEW OF RESEARCH INVOLVING HUMAN PARTICIPANTS**

**Guidance Notes**

These notes are intended to be read when completing the application form for ethical review of research involving human participants. The University's policy and procedures on research ethics may be found at <http://www1.uwe.ac.uk/research/researchethics.aspx>. Please address any enquiries which are not covered in these notes to the contacts below for all Faculty Research Ethics Committee's to which you are submitting your application.

This form may also be completed by researchers outside UWE who plan to conduct research within the University. (Note: Where a researcher has already obtained REC approval from another institution it may not be necessary to submit another application but you will need to send details of the research and evidence of approval to the REC chair before access may be granted to UWE staff and students.)

**Research Ethics Committee contacts:**

	Name	Email	Telephone
University Research Ethics Committee (UREC)		<a href="mailto:researchethics@uwe.ac.uk">researchethics@uwe.ac.uk</a>	0117 32 82872
<b>Note: UREC reviews applications for ESRC-funded research, research involving surveying on a University-wide basis, and research conducted by staff in the Central Services.</b>			

**Please note commencing from the 1<sup>st</sup> September 2014 all other applications should be directed to RBI, Research Admin, Committee Services.**

**Research Admin – Committee Services**

	Team leader	<a href="mailto:researchethics@uwe.ac.uk">researchethics@uwe.ac.uk</a>	0117 32 81170
	Research Administrator	<a href="mailto:researchethics@uwe.ac.uk">researchethics@uwe.ac.uk</a>	0117 32 81167

### External ethics approval

Where the work has already been subjected to ethical scrutiny, for example, by an NHS Research Ethics Committee through the National Research Ethics Service (NRES), you should indicate this on the form.

If your research involves NHS patients (including tissue or organs), or NHS data, you will usually need to get NHS REC approval. The UWE procedures recognise the burden placed on the researcher in applying for NHS REC approval. In order to assist PIs in this as far as possible, you are recommended to apply for NHS REC ethics approval first (using the IRAS form) and submit the letter of approval to your FREC or to UREC (as applicable). Where UWE is the sponsor for the study your FREC Chair will need to see the application before it can be authorised by the sponsor representative. This approach has been designed to retain the right of ultimate 'sign off' by the University without having to go through a separate protracted University process. It is important that PIs conducting research in the NHS appreciate that both UWE and NHS Ethics clearance will be needed and are separate. (Achievement of the one does not guarantee success with the other).

If you have already received ethical approval from an external Research Ethics Committee, you should provide evidence of this to UREC/FREC.

### Student applications

For student applications, supervisors should ensure that all of the following are satisfied before the study begins:

- The topic merits further research;
- The student has the skills to carry out the research;
- The participant information sheet or leaflet is appropriate;
- The procedures for recruitment of research participants and obtaining informed consent are appropriate.

### Declaration

This should be completed once all the following questions have been answered. Where the application is from a student, **a counter-signature from the supervisor is also necessary**. Applications without a supervisor signature will not be processed.

### Question 1: Details of the proposed research – aims and objectives of the research

This should provide the reviewer of the application with sufficient detail to allow him/her to understand the nature of the project and its rationale, in terms which are clear to a lay reader. Do not assume that the reader knows you or your area of work. It may be appropriate to provide a copy of your research proposal.

**Question 2:** Details of the proposed research – Research methodology to be used

You should explain how you plan to undertake your research. A copy of the interview schedule/ questionnaire/observation schedule/focus group topic guide should be attached where applicable.

**Question 3:** Participant details – Participants from vulnerable groups

You must indicate if any of the participants in your sample group are in the categories listed. Any Department of Health funded research involving participants who might not have the capacity to consent may need to go through the new Social Care Research Ethics Committee (<http://www.screc.org.uk/>), unless it is already being reviewed through NRES. If your research subjects fall into any of the specified groups, you will need to justify their inclusion in the study, and find out whether you will require a Disclosure and Barring Service (DBS) (formerly Criminal Records Bureau -CRB) check.

Members of staff requiring DBS checks should contact Human Resources [hr@uwe.ac.uk](mailto:hr@uwe.ac.uk). DBS checks for students will usually be organised through the student's faculty, but students in faculties without a DBS countersignatory should contact Leigh Taylor ([Leigh.Taylor@uwe.ac.uk](mailto:Leigh.Taylor@uwe.ac.uk)).

Please note: Evidence of a DBS check should take the form of an email from the relevant countersignatory confirming the researcher has a valid DBS check for working with children and/or vulnerable adults. It will be the responsibility of the applicant to provide this confirmation.

**Question 4:** Participant details – Determination of sample size, identification and recruitment of participants

In this section, you should explain the rationale for your sample size and describe how you will identify and approach potential participants and recruit them to your study.

**Question 5:** Informed consent and withdrawal

Informed consent is an ethical requirement of the research process. Applicants should demonstrate that they are conversant with and have given due consideration to the need for informed consent and that any consent forms prepared for the study ensure that potential research participants are given sufficient information about a study, in a format they understand, to enable them to exercise their right to make an informed decision whether or not to participate in a research study.

Consent must be freely given with sufficient detail to indicate what participating in the study will involve. Withdrawal from future participation in research is always at the discretion of the participant. There should be no penalty for withdrawing and the participant is not required to provide any reason.

You should describe how you will obtain informed consent from the participants and, where this is written consent, include copies of participant information sheets and consent forms. Where other forms of consent are obtained (eg verbal, recorded) you should explain the processes you intend to use. See also data access, storage and security below.

**Question 6:** Confidentiality/anonymity

You should explain what measures you plan to take to ensure that the information provided by research participants is anonymised/pseudonymised (where appropriate) and how it will be kept confidential. In the event that the data are not to be anonymised/pseudonymised, please provide a justification.

Personal data is defined as ‘personal information about a living person which is being, or which will be processed as part of a relevant filing system. This personal information includes for example, opinions, photographs and voice recordings’ (UWE Data Protection Act 1998, Guidance for Employees).

**Question 7:** Data access, storage and security

Describe how you will store the data, who will have access to it, and what happens to it at the end of the project. If your research is externally funded, the research sponsors may have specific requirements for retention of records. You should consult the terms and conditions of grant awards for details.

It may be appropriate for the research data to be offered to a data archive. If this is the case, it is important that consent for this is included in the participant consent form.

UWE IT Services provides data protection and encryption facilities - see [http://www.uwe.ac.uk/its-staff/corporate/ourpolicies/intranet/encryption\\_facilities\\_provided\\_by\\_uwe\\_itservices.shtml](http://www.uwe.ac.uk/its-staff/corporate/ourpolicies/intranet/encryption_facilities_provided_by_uwe_itservices.shtml)

**Question 8:** Risk and risk management – Risks faced by participants

Describe ethical issues related to the physical, psychological and emotional wellbeing of the participants, and what you will do to protect their wellbeing. If you do not envisage there being any risks to the participants, please make it clear that you have considered the possibility and justify your approach.

**Question 9:** Risk and risk management – Potential risks to researchers

Describe any health and safety issues including risks and dangers for both the participants and yourself (if appropriate) and what you will do about them. This might include, for instance, arrangements to ensure that a supervisor or co-researcher has details of your whereabouts and a means of contacting you when you conduct interviews away from your base; or ensuring that a ‘chaperone’ is available if necessary for one-to-one interviews.

**Question 10:** Publication and dissemination of research results

Please indicate in which forms and formats the results of the research will be communicated.

**Question 11:** Other ethical issues

This gives the researcher the opportunity to raise any other ethical issues considered in planning the research or which the researcher feels need raising with the Committee.

## **APPLICATION FOR ETHICAL REVIEW**

This application form should be completed by members of staff and Phd/ Prof Doc students undertaking **research which involves human participants**. U/G and M level students are required to complete this application form where their project has been referred for review by a supervisor to a Faculty Research Ethics Committee (FREC) in accordance with the policy at <http://www1.uwe.ac.uk/research/researchethics>. For **research using human tissues**, please see separate policy, procedures and guidance linked from <http://www1.uwe.ac.uk/hls/research/researchethicsandgovernance.aspx>

Please note that the research should not commence until written approval has been received from the University Research Ethics Committee (UREC) or Faculty Research Ethics Committee (FREC). You should bear this in mind when setting a start date for the project.

**This form should be submitted electronically to the Officer of the Research Ethics Committee (see list above at page 1) together with all supporting documentation (research proposal, participant information sheet, consent form etc).**

Please provide all the information requested and justify where appropriate.

*For further guidance, please see <http://www1.uwe.ac.uk/research/researchethics> (applicants' information) or contact the officer for UREC/your Faculty Research Ethics Committee (details at page 1).*

### **Project Details:**

Project title	The Impact of Visible Differences on Intimacy and Intimate Relationships (this specific part of the project is entitled "Exploring Experiences of Visible Difference, Intimacy and Intimate Relationships")		
Is this project externally funded?	No		
If externally funded, please give details of project funder	n/a		
Proposed project start date	01 May 2015	Anticipated project end date	31 January 2016

### **Applicant Details:**

Name of researcher (applicant)	Nicholas David Sharratt
Faculty and Department	Health and Applied Sciences: Health and Social Sciences: Centre For Appearance Research

Status  (Staff/ PG Student/MSc Student/Undergraduate)	PhD Student
Email address	Nick.sharratt@uwe.ac.uk
Contact postal address	Room 2L13, Frenchay Campus, UWE
Contact telephone number	0117 381891
Name of co-researchers (where applicable)	

*(for completion by UWE REC)*

*Date received:*

*UWE REC reference number:*

<b>For All Applicants:</b>	
Has external ethics approval been sought for this research?	No
If yes, please supply details:	

<b>For student applicants only:</b>	
Name of Supervisor / Director of Studies  (for PG/MSc and UG student applicants) <sup>1</sup>	Professor Nichola Rumsey
Details of course/degree for which research is being undertaken	PhD

***<sup>1</sup>For student applications, supervisors should ensure that all of the following are satisfied before the study begins:***

- The topic merits further research;
- The student has the skills to carry out the research;
- The participant information sheet or leaflet is appropriate;

- The procedures for recruitment of research participants and obtaining informed consent are appropriate.

Department of Supervisor / Director of Studies	Health and Applied Sciences: Health and Social Sciences: Centre For Appearance Research
Supervisor's / Director of Studies' email address	Nichola.rumsey@uwe.ac.uk
Supervisor's / Director of Studies' telephone number	0117 383989
Supervisor's / Director of Studies' comments:	

**Details of the proposed work:**

**PLEASE COMPLETE ALL SECTIONS. IF YOU THINK THE QUESTION IS NOT APPROPRIATE, PLEASE STATE WHY.**

**1. Aims, objectives of and background to the research:**

**Summary of aims and objectives**

The aims of this research are to better understand the impact of disfiguring conditions or visible differences upon intimacy and intimate relationships in an adult population. Despite suggestions in the existing literature that visible differences can negatively impact upon experiences of intimate relationships, the area remains under-researched. In conducting this research the Centre for Appearance Research will be responding to clinical practitioner and researcher calls for a greater understanding of this sphere of human activity. In addition to addressing this gap in the literature and answering these calls, in due course the study outcomes will be utilised in developing a measurement tool so that any impact of visible difference upon intimate relationships can be measured. This tool will then be used to identify those who may benefit from treatment or intervention. The development and validation of the measurement tool will be subject to a separate ethical application at a later date.

In addition to the main study which will consider the experiences and understandings of those that have a visible difference, an ancillary study will seek to understand the experiences and understandings of those that are or have been the partner of someone who has a visible difference. This perspective is largely missing from the existing research and primarily only referred to in passing, such as when a participant with a visible difference mentions their partner or former partner. Increasing our knowledge in this area is therefore important and would be informative and interesting to those with visible differences, researchers and practitioners in the field as well as forming the basis upon which appropriate forms of support and intervention will be developed.

**Background**

Visible differences or disfiguring conditions have been defined by Kent and Thompson (2002) as 'potentially noticeable differences in appearance that are not culturally sanctioned' and they highlight the three main causes as being congenital conditions, traumatic events and disease. It is well established that these differences can impact negatively upon an individual's life and are associated with a variety of psychosocial difficulties. These difficulties can include depression, social anxiety, reduced quality of life and social avoidance (Rumsey, Clarke and White, 2003). Furthermore, the individual's subjective evaluation of their appearance has been shown to provide a more powerful indication of the likelihood of psychological distress than an objective, physical measure of the difference (Ong et al, 2007; Moss, 2005).

These difficulties with psychological adjustment may impact upon an individual's interpersonal relationships as negative responses from others and can lead to a preoccupation with appearance, anticipation of negative reactions, sub-optimal interaction styles and social avoidance (Rumsey and Harcourt, 2004). An avoidant response has been further conceptualised as maladaptive by Newell (1999; 2000) whose fear avoidance model posits that fear experienced as a result of a disfigurement in

relation to the anticipated reactions of others may be met by confrontation or avoidance. Avoidant responses reinforce themselves and deprive the individual of the opportunity to develop the effective communication and social skills that predict positive outcomes (Clarke, 1999).

It is consistent with these explanations of the social and psychological impact of visible differences that visible difference will impact upon intimacy, which has been defined as the process in which one person expresses important and relevant feelings and information to another and comes to feel understood and cared for as a result (Manne and Badr, 2010). It is important to understand any such impact as intimate relationships constitute a principal component of adult human life and have been described as natural, protective and an essential element of our adaptation, functioning and ability to lead healthy, happy lives (Popovic, 2005).

The potential impact of visible difference upon intimacy has been borne out by the limited existing literature. Those who have visible differences reported difficulties in initiating and maintaining intimate relationships. This was so in relation to adolescents and young adults (Carpentier et al, 2011) and also an adult population (O'Brien et al, 2012). Indeed, social avoidance and fear have been explicitly cited in explanation of such difficulties, again in both adult (Batty, McGrath and Reavey, 2014; Mathias and Harcourt, 2014; Magin et al, 2010) and adolescent/young adult populations (Griffiths, Williamson and Rumsey, 2012; Fox, Rumsey and Morris, 2007).

Whilst research specifically considering intimacy and visible differences is limited, a further body of condition specific work implicates visible differences in intimacy difficulties through examining the impact of certain appearance altering conditions. These studies demonstrate a negative impact across a range of measures and a variety of conditions including head and neck cancer (Low et al (2009), severe atopic eczema (Finlay, 1996; Long et al, 1993), psoriasis (Sampogna et al, 2007) vitiligo (Porter et al, 1990), burn injuries (Connell, Coates and Wood (2012), disability (Taleporos and McCabe, 2002) and amputation (Geertzen, Van Es and Dijkstra, 2009). These studies, however, do not clarify the role of appearance dissatisfaction or attempt to separate it from any effect of the disease or condition aetiology. They are perhaps best represented by Connell et al (2014) whose work with burns patients identified that the psychological impact of burns and their impact upon sexuality, interpersonal relationships and body image did not significantly improve for survivors, regardless of physical functional recovery. It is conceivable that patients' burn sites remained scarred despite functional recovery but this was not measured. Consequently the work highlights that aetiology itself may not be critical and that some other factors impact adjustment. The work is, however, unable to link this definitively with appearance concerns.

The limitations of the condition specific studies coupled with the small number of studies that have specifically considered visible differences and intimacy, the fact that several of these were concerned only with adolescent and/or young adult populations and the importance of intimacy, all highlight the need for further research in the area. This need has been explicitly referred to in the recent literature (Connell et al, 2014; Griffiths et al, 2012; Rumsey and Harcourt 2012; 2012a; Rumsey, 2012). The use of the data in developing a measurement tool to assess the impact of visible difference on an individual's ability to engage in intimate relationships will also answer a need

communicated to the Centre for Appearance Research by clinical practitioners.

The ancillary study will involve interviewing current or former partners of those with a visible difference in order to gain an understanding of the perspective of the partners of those with an altered appearance. To date, very few pieces of research have attempted to do this and those that do have examined the impact of a specific condition.

Once again, such research may confound appearance and disease aetiology but, looking specifically as psoriasis, Wahl, Gjengedal and Hanestad (2002) identified feelings of guilt arising from participants considering themselves a burden on their partners and that the physical manifestation of the condition also represented a barrier to physical intimacy and intercourse. This was attributed not only to pain but also to participants considering their bodies to be disgusting and unattractive and transferring these feelings onto their partner. These feelings, however, may not represent those held by partners themselves. Whilst the lack of research means that this is a rather tentative argument and Wahl, Gjengedal and Hanestad (2002) did not include partners as participants, it may be made by drawing upon research with participants who had two different conditions (testicular cancer or Hodgkin's Disease). Hannah et al (1992) found that those with these conditions were more likely than their partners to report a decrease in attractiveness as a result of the condition. The authors argue that it may be reassuring to survivors of those conditions to know that their partners did not (generally) report any decrease in attractiveness levels.

The paucity of research that considers the partner perspective and the apparent discrepancy between what an individual with an appearance altering condition believes about the experiences of their partner and the partner's own account justifies this as an area in need of further study. The ancillary study will begin to redress the lack of understanding of this overlooked area.

## **2. Research methodology to be used (include a copy of the interview schedule/ questionnaire/ observation schedule where appropriate):**

In order to meet the aims and objectives of this research a qualitative methodology will be employed. A qualitative methodology is appropriate for a sensitive topic such as this (Elmir, Schmied, Jackson and Wilkes, 2011) and ensures that the participants' voices are heard and given priority whilst studying this under-researched area.

Within this qualitative paradigm, semi-structured individual interviews will be conducted with eligible participants identified in accordance with sections 3 to 5 below. These interviews will be flexibly directed by employing the interview guide (attached) and will, at the choice of each individual participant, be undertaken remotely via electronic methods of communication (phone or skype) or in person via a face-to-face interaction. The interviews will be audibly recorded and transcribed before being thematically analysed. A summary of the identified themes will be provided to each participant that expresses a desire to receive this information and their thoughts or comments on the analysis welcomed.

This summary of the research methodology incorporates a number of decisions that have

been based upon methodological and ethical considerations and which will now be briefly elucidated.

Individual interviews will be utilised as they constitute the primary technique for qualitative data collection (Aborisade, 2013). Semi-structured interviews will be employed as they allow the researcher to ensure a balance is achieved between a level of flexibility that allows the participant to express themselves and the need to ensure that the focus of the research is not obscured (Kelly, 2010). To ensure that the suggested questions and broad topic areas are appropriate to the object of investigation but are unlikely to cause participants harm or distress the interview guide (which will be used as a prompt rather than followed slavishly) has been developed in consultation with Professor Nichola Rumsey and Dr Alex Clarke, a clinical psychologist and research practitioner.

Individual interviews will be used rather than focus groups as interviews are considered a more suitable and ethical method of data collection for this research. It must be acknowledged that debate exists here. Some researchers have argued that focus groups are a suitable method to deploy in researching sensitive topics (Wilkinson, 2008), including research concerned with sex, and can lead to enhanced disclosure within a comfortable and secure environment (Frith, 2000) in which individual participants are not compelled to answer any particular question (Barbour, 2010). These arguments are countered by claims that the social context of a focus group may inhibit some members and lead to them censoring personal disclosure (McParland and Flowers, 2012) and even create an environment in which undue influence, censorship and conformity can arise as issues (Wooten and Reed, 2000).

Braun and Clarke (2013) acknowledge that individual interviews are often considered ideal for sensitive issues but, at the same time, some participants may prefer a group setting. They conclude, however, that interviews are most suitable for examining individual experiences, understandings and perceptions in relation to issues in which participants hold a personal stake. Focus groups, they argue, are generally more appropriate where participants have no personal stake in the topic of discussion.

Offering participants a choice of an individual interview and a focus group may have represented an ethical solution to the question of which method of data collection to employ. Indeed, primarily due to logistical issues, the methods have previously been combined (Egan, Harcourt and Rumsey, 2011). Given concerns, however, relating to the dissimilar nature of the social interaction and the data generated by focus groups and individual interviews and the related argument that focus group data represent collective and negotiated rather than individual understandings (Lehoux, Poland and Daudelin 2006; Hollander, 2004), this option has been discounted in favour of ensuring consistency in the production and nature of data.

In light of these arguments, the nature of this research and its participants and the desire for consistency it is considered that individual interviews constitute the more appropriate and ethical means of data collection. The literature introduced in section 1 above suggests that some participants that will be recruited to this study may be experiencing a level of difficulty in their psychosocial adjustment, may suffer from some level of social anxiety (Rumsey, Clarke and White; 2003) and adopt avoidant behaviours (Newell, 2000:

1999). Exposing such individuals to a focus group scenario and asking that they discuss the intersection of visible difference and intimacy, two personal and sensitive topics, may lead to distress, embarrassment, self-presentational concerns and social anxiety. It could therefore be ethically dubious and the more controlled environment within which individual interviews can be conducted and in which the safeguards discussed in section 8 can be consistently implemented, is preferred.

Whilst participants will not be offered a choice between individual interviews and focus groups, they will be offered a choice of whether the interviews are conducted in person or remotely via phone or skype (which is here considered analogous to phone interviews). This choice is being offered to ensure participants are as comfortable as possible (Elmir, Schmied, Jackson and Wilkes, 2011) and have the option of participating from a familiar location (McCoyd and Kerson, 2006). This choice also acts to empower participants and place them at the centre of the research process (Trier-Bieniek, 2012).

Offering this choice is considered especially important within the context of the planned research and the characteristics that some of the participants may display (discussed above). It will therefore help to ensure that the highest ethical standards are maintained. Both Elmir, Schmied, Jackson and Wilkes (2011) and Egan, Harcourt and Rumsey (2011) highlight that the use of phone interviews may help researchers access hard to reach populations. It is possible that the impact of visible differences renders some potential participants as difficult to reach, especially those who may react to their status in an avoidant manner and may find the prospect of speaking to someone in person intimidating and potentially upsetting. Offering a choice will therefore ensure the research is inclusive and enable a broader and more representative sample of participants to be recruited.

Whereas the impact upon the nature of the data precludes offering participants a choice between focus groups and individual interviews, there is a burgeoning recognition that remote methods of communication can produce high quality data comparable to that produced in physically proximate interaction. Indeed, despite face-to-face interviews often being presented as the 'gold standard' of interviewing (Novick, 2008) and the claim that remote interviews may be shorter and less detailed than ones conducted in person (McCoyd and Kerson, 2006) the phone is increasingly used as a method for qualitative interviews (Burke and Miller, 2001) and can be an effective method for doing so (Miller, 1995). Claims such as McCoyd and Kerson's (2006) lack a substantive empirical basis as there is no evidence that phone interviews lead to poorer quality or distorted data, less data or data that are more difficult to interpret (Novick, 2008).

Instances of the method being employed in connection with sensitive issues (Trier-Bieniek, 2012) and within the field of visible differences (Egan, Harcourt and Rumsey, 2011; Dures, Rumsey, Morris and Gleeson, 2011) support Sturges and Hanrahan's (2004) contention that data generated through phone interviews does not differ from that generated in face-to-face interviews. Novick (2008) argues that phone interviews may be particularly appropriate for sensitive topics as the medium allows participants to relax and facilitates the calm disclosure of sensitive information. Such claims are mirrored by Braun and Clarke (2013) who list the benefits of virtual interviews as including their potential suitability for sensitive topics arising from the fact they are more anonymous and less likely to lead to participants feeling judged or the effects of social pressure.

These benefits may be particularly pertinent where the researcher has made a concerted effort to establish a level of rapport prior to the remote interview taking place (Evans, Elford and Wiggins, 2008). This rapport will be generated during the pre-interview contact between the researcher and each participant (see section 4, below).

The lack of any established negative impact upon the data arising from the use of phone interviews coupled with the benefit that some participants may experience and the desire to empower participants to make choices about how the research should be conducted thus justifies offering participants the choice about the medium through which they will engage with the research.

In order to ensure participants' comfort and convenience each participant will be offered the choice of the time at which the interview will occur and where it will involve a face-to-face interview, the location. The location may be on the premises of the University of the West of England, at a public place that is convenient for the participant (the researcher will make necessary arrangements to secure a room in a local library or community centre) or, if there is nowhere else that the participant feels able to be interviewed, in the home of the participant. This is considered further in section 9.

The resulting data will be analysed using thematic analysis as described by Braun and Clarke (2014; 2013; 2006). This method of analysis is appropriate as it is useful for applied work (Braun and Clarke, 2014) and allows the researcher to systematically organise and identify commonalities of meaning and experience (Braun and Clarke, 2013).

A summary of the key themes and sub-themes identified in the analysis will be provided to each participant that indicates a desire to receive this and their comments or thoughts welcomed. It will be made clear that the themes have been derived from a sample of interviews. This will provide participants with a summary of the research findings so that they may be considered and commented upon, as Walsh and Downe (2006) view as a hallmark of quality qualitative research. It is also hoped that it will foster a sense of inclusiveness as well as act as an overt expression of the researcher's respect for and gratitude to the participants.

### **3. Selection of participants:**

**Will the participants be from any of the following groups?** *(Tick as appropriate)*

- ☐ Children under 18
- ☐ Adults who are unable to consent for themselves<sup>2</sup>
- ☐ Adults who are unconscious, very severely ill or have a terminal illness
- ☐ Adults in emergency situations
- ☒ Adults with mental illness (particularly if detained under Mental Health Legislation)
- ☐ Prisoners
- ☐ Young Offenders

- ☐ Healthy Volunteers (where procedures may be adverse or invasive)
- ☐ Those who could be considered to have a particularly dependent relationship with the investigator, e.g. those in care homes, medical students
- ☒ Other vulnerable groups
- ☐ None of the above

*(<sup>2</sup> Please note, the Mental Capacity Act requires all intrusive research involving adults who are unable to consent for themselves to be scrutinised by an NHS Local Research Ethics Committee – Please consult the Chair of your Faculty Research Ethics Committee, or Ros Rouse (UWE Research Governance Manager) for advice: [ros.rouse@uwe.ac.uk](mailto:ros.rouse@uwe.ac.uk))*

**If any of the above applies, please justify their inclusion in this research:**

Participants in the main study will be those that self-identify as having a visible difference. Whilst this, in itself, does not deem them vulnerable there is a body of research referred to in section 1 which indicates that for a proportion of the population eligible population, visible differences may be comorbid with psychological distress and adjustment difficulties. These may include some forms of mental illness such as depression and anxiety but will not include any adults detained under applicable legislation. The option of excluding any participant with any co-morbid mental health issues was considered but after consulting with a clinical psychologist it was felt that it would potentially deny a significant portion of the population a voice in the research and would also mean that the full range of experiences may not be captured. It may also be considered unnecessarily stigmatising and even unethical to refuse to interview those who have, for example, diagnosed depression on the basis of the diagnosis per se and without considering whether the condition actually impacts upon the individual's ability to consent or to safely participate in the research. Excluding all those with diagnosed conditions may also have meant that for those with mild forms of anxiety or depression (or other conditions) participation would be contingent upon whether a diagnosis had been sought as many such people may remain undiagnosed.

Despite the decision to include those with controlled or and less impactful mental health conditions and in order to minimise any risk to participants and ensure that consent can be freely given and as described in section 4 (below), potential participants with diagnosed mental health conditions that are uncontrolled (by medication or intervention) and which have a significant impact upon the activities of daily life will not be eligible to participate in this research.

At this juncture it is also worth referring to sections 8 and 9, below. These detail the considerable experience that the researcher has as a Samaritans listener. Many of the people calling that service voluntarily disclosed mental health conditions and so the researcher is well used to interacting with those that have some such concern and is confident in his ability to adopt a sensitive but professional manner throughout the interview process.

***Note: If you are proposing to undertake research which involves contact with children***

***or vulnerable adults, you may need to hold a valid DBS (Disclosure and Barring Service, formerly Criminal Records Bureau – CRB) check.***

***Where appropriate, please provide evidence of the check with your application.***

Whilst it may not be strictly necessary for this research, the researcher holds a DBS certificate with enhanced disclosure and has provided this to the University in connection with ad hoc assistance he has provided on other CAR research projects involving contact with children in schools. A scanned copy is attached with this application.

**4. Please explain how you will determine your sample size/recruitment strategy, and identify, approach and recruit your participants. Please explain arrangements made for participants who may not adequately understand verbal explanations or written information in English.**

A purposive sampling strategy will be adopted and the study will be open to individuals who are at least 18 years old, self-identify as having a visible difference or having had a visible difference if the difference is no longer apparent and are able to communicate verbally and in the English language. For the purposes of the ancillary partner study, the inclusion criteria will be the same with the exception of the visible difference criteria. For this arm of the study participants will be those that identify themselves as having or having had a partner who has a visible difference rather than those that identify as having a visible difference themselves.

Due to limited resources and limited researcher language skills, it will not be possible to make any arrangements for participants who are not able to adequately understand verbal explanations or written information in English. For the protection of vulnerable persons, to avoid related issues regarding the capacity to provide informed consent and in order to attempt, so far as possible, to isolate the impact of visible differences rather than comorbid issues of significant and impactful mental health concerns, participants also be informed that those with diagnosed mental health conditions that remain uncontrolled by medication or intervention and which have a significant impact upon their ability to engage in everyday activities cannot be interviewed. They will be asked to confirm that they are eligible for the study and will be excluded from participation if they are unable to provide this confirmation.

Whilst it is not possible to conclusively predetermine a sample size for qualitative work such as this, Braun and Clarke (2013) advise that a small (6-10 participants) to moderate (10-20 participants) sample size is used for interview studies examining the experiences of those that are being interviewed. In light of the possibility of demographic and experiential factors impacting upon participants experiences (e.g. sex, marital status (see below), nature of the visible difference (congenital or acquired via disease process or trauma)) it is anticipated that the sample size for the main study will be toward the greater end of this spectrum in order to capture a broad a range of experiences and understandings from a relatively heterogeneous sample of participants. This heterogeneity justifies going beyond the sample size of twelve that Guest, Bunce and Johnson (2012) recommend for studies of homogenous groups concerned with a narrow sphere of activity. The ancillary (partner) study, however, will involve fewer participants and remain a small study (as defined by Braun and Clarke, 2013) of approximately 6-10

participants.

In order to ensure that neither study over-recruits and collects more data than is necessary to answer the research question and in acknowledgement of Guest, Bunce and Johnson's (2012) findings that 73% of data codes were identified within the first six interviews and 92% within the first twelve (albeit with a more homogenous population), the data will be monitored by the researcher and recruitment stopped or postponed should data or thematic saturation be realised. Whilst this concept differs from the theoretical saturation of grounded theory and remains relatively poorly defined and operationalised (O'Reilly and Parker, 2012) it commonly refers to the point at which no new themes emerge and additional data does not generate new information (Braun and Clarke, 2013; O'Reilly and Parker, 2012). This monitoring will be conducted informally as the researcher conducts, transcribes and listens to each interview and more formally as the data is analysed in an iterative fashion as close to the point at which it is captured as possible. Should the researcher judge that data or thematic saturation has occurred (in either study) the existing data set will be analysed. If new themes do not continue to emerge then data collection will be postponed. If themes continue to emerge it will restart.

If, after analysing the data generated in the performance of the main study, thematic saturation is not adjudged to have been achieved or if it appears that the sample fails to represent the distinct experiences of a group of potential participants, recruitment will recommence. In the event this occurs because a group of potential participants have not been represented, this will be with more focussed eligibility criteria in order to address this deficit.

By way of example the limited existing literature suggests that in the case of acquired difference, being partnered/un-partnered at the time the difference arises impacts differently upon experience and adjustment (Connell et al, 2014; O'Brien et al, 2012; Carpentier et al, 2011; Carpentier and Fortenberry, 2010; Chapple and McPherson, 2004; Porter, 1990). In light of such findings, it would be informative to interview participants with acquired differences who were partnered and those who were not in a relationship at the time the difference was acquired. If the initial sample does not include such persons, a targeted attempt will be made to address this limitation.

Potential participants will be made aware of the study via adverts placed on UWE and CAR's web and social media pages. Relevant charities and support groups (with whom CAR already has excellent relationships) will be approached and asked to advertise the study on their web-site, social media, through e-mails/newsletters and in other publications. Relevant organisations include: Changing Faces; the Cleft and Lip Palate Association; the British Skin Foundation and the Healing Foundation. The advert will provide a brief description of the study and the researcher's contact details. Interested persons will then be able to contact the researcher through the medium of their choice (phone or e-mail). The researcher will provide a participant information sheet and consent form (both attached) and will either arrange to contact the participant after a certain amount of time has elapsed or await further contact from the participant. At this later contact arrangements for the interview will be made if the participant is willing to proceed. This method of recruitment has the ethical advantage of researcher passivity. Participants will have actively responded to the advertisement and so no individual will

be directly asked to participate or placed under any pressure from the researcher to do so.

A colleague from CAR currently conducting a research study has asked that any participants in that study who may be interested in participating in future research related to intimacy volunteer their e-mail address. A brief e-mail advertising the study and providing the researcher's contact details will be sent to those e-mail addresses which have been provided. No further e-mails will be sent to the recipients of those e-mails unless and until they contact the researcher indicating a desire to participate. Similarly and to maintain confidentiality and anonymity, these potential participants will each be blinded to the e-mail addresses of the other recipients.

Communications with potential participants responding to the study advertisements will be conducted in a timely and sensitive manner and by adopting a sensitive, interested and empathetic tone (Chapple, 1999). Furthermore, they will be used in order to establish some level of pre-interview rapport with participants. Evans, Elford and Wiggins (2008) consider this important for interviews that are conducted remotely where opportunities to build this relationship are somewhat limited whilst Mealer and Jones (2014) identify the initial contact and consent process as a suitable time for such rapport to be established.

**5a. What are your arrangements for obtaining informed consent whether written, verbal or other? (where applicable, copies of participant information sheets and consent forms should be provided)**

Once individuals respond to the advertisements requesting participants they will be provided with a brief description of the study either verbally (if they phone) or in an e-mail if they choose to use this method of communication. If the potential participant e-mails the researcher then the researcher will also attach to the e-mail a copy of the participant information sheet (attached) and consent form (also attached) to that initial e-mail. If contact is made via the phone then the researcher will ask the participant whether they would like to receive the participant information sheet and consent form through the post or attached to an e-mail and shall then send it to them. Potential participants will be asked to read the participant information sheet and consent form and consider whether they wish to participate. They will be asked to contact the researcher again if they do wish to participate. The researcher will also offer to contact them at a convenient time and through the medium of their choice if they prefer for this to happen.

Practical arrangements for the interview (medium of communication, date, time and location) will then be made with those individuals who do wish to participate. Participants who choose to participate remotely via skype or the phone will be asked whether it is possible to sign, date and scan or post the consent form to the researcher. If so, the researcher will also sign and date the form upon receipt and immediately prior to the interview commencing shall confirm verbally with the participant that the participant has seen both the participant information sheet and consent form, has signed and dated the consent form and that the consent remains valid. If the participant is not able to post or scan a signed version of the consent form to the researcher, they will be asked to confirm in the body of an e-mail that they provide the consent required by the consent form. They will be asked to attach the copies of the participant information sheet and

consent form that the researcher has supplied to them to this e-mail. If none of these methods of consent are possible then immediately prior to the interview researcher shall ask the participant to confirm that they have read and understood the participant information sheet and consent form, shall read the operative consent provisions to the participant and ask for verbal confirmation that they provide the consent detailed and the researcher shall indicate that this has been done on the section of the consent form that participants ordinarily sign before signing and dating the form themselves. In respect of any interviews for which consent is provided on this basis, the participant will be asked to confirm that they have provided consent at the start of the interview so that the recording reflects this is the case.

Participants who are interviewed in person will be provided with a further copy of the participant information sheet and consent form immediately prior to the interview commencing. They will be asked whether they have read and understood these before and provided with the opportunity to re-read them before verbal consent is taken by the researcher reading the consent section of consent form and the participant expressly indicating their consent. This will be confirmed by the participant signing and dating the consent form, which shall also be signed and dated by the researcher.

Throughout the process of dealing with potential participants' expression of interest in the study, providing information and participants giving their consent, the researcher will act in a professional and courteous manner and be careful to ensure no individual is placed under any undue pressure to participate.

**b. What arrangements are in place for participants to withdraw from the study?**

As the participant information sheet (attached) details, participants will be able to withdraw from the study at any point prior to the interview being conducted and at any point during the interview by informing the researcher of their desire. Where such withdrawal occurs, all data and information held by the researcher and related to that participant will be destroyed, deleted or discarded. Any interview data will not be transcribed or analysed. Should any participant wish to withdraw their data after the interview, they will be able to do so by informing the researcher via phone or email of their wishes. In such case no further use will be made of the data related to that participant and all data and information held by the researcher and related to that participant will be destroyed, deleted or discarded. As the participant information sheet indicates, it will not be possible to withdraw the data relating to that participant from any presentations or publications that have been made or published prior to the date of withdrawal.

Data will be held by using a code constituted by the date upon which an interview occurs and selected details provided by the participant on the consent form or in an e-mail where the signed consent form cannot be obtained. This information will be recorded on the hard copies of the consent forms and on all copies of the interview transcripts. The consent forms (which will be securely stored, see section 7) will be the only record that links a participant with the data that relates to them. This will be done only to enable participants to withdraw their data.

**6. If the research generates personal data, please describe the arrangements for maintaining anonymity and confidentiality or the reasons for not doing so.**

All participants will be assigned a pseudonym that will be used when transcribing, analysing and reporting the research data. Any place names or the names of other persons will be altered or omitted at the transcription stage. As such, the data will be anonymised as close to the point at which it is collected as is possible.

As detailed in section 5b, all research data will be held by using a code constituted by the date upon which an interview occurs and selected details provided by the participant on the consent form or in an e-mail where the signed consent form cannot be obtained. This information will be recorded on the hard copies of the consent forms and on all copies of the interview transcripts. The consent forms (which will be securely stored, see section 7) will be the only record that links a participant with the data that relates to them. This will be done to ensure participants are able to withdraw their data if they wish.

The consent form for the main study contains a space for participants to provide their email address if they are willing to be emailed once the measurement scale has been developed and is ready for testing and validation. These email addresses will be used only for that purpose. The consent forms (and any email consent confirmations) will be stored in hard copy only, will be stored separately from the research data so that they cannot be linked by anyone other than the researcher and Professor Nichola Rumsey. They will be stored in a locked filing cabinet in a room on the University premises occupied exclusively by CAR staff, PhD students and occasionally visitors to CAR or MSc placement students. The room in which the consent forms will be stored is locked when it is not occupied.

Electronic copies of all e-mail correspondence related to potential participants and participants will be retained by the researcher in his UWE staff e-mail account and stored in a dedicated folder. All emails will be deleted once data collection has ceased.

It is conceivable that participants in the main study (those with a visible difference) and in the ancillary study (partners of those with a visible difference) may be known to one another. In light of this and even with the intended use of pseudonyms it is theoretically possible that one participant in one study may be able to, or may believe that they are able to, identify a participant in another study should they read any publication of the study results. Demographic data provided in any publication of the study outcomes will be presented in a way so as to reduce the likelihood of this occurring. Similarly, direct quotations will be carefully chosen in order to minimise this possibility. The participant information sheet and consent form explicitly specify that direct quotations may be used and published. In addition, participants will be asked, as part of the debriefing session at the end of the interview (the content so of which is indicated at the end of the interview guide), whether they have said anything or recounted any episode that they would like to exclude from being the subject of any direct quotations or from being explicitly referred to in any publication of the study outcomes.

The nature of the subject of investigation means that it is conceivable, though perhaps unlikely, that participants may recount historical or current episodes of sexual abuse or harassment, whether as victim or perpetrator. As detailed in the participant information sheet, this may require that confidentiality be breached in certain circumstances. These circumstances are those prescribed by the British Psychological Society's Code of Ethics

and Conduct (by which the researcher is bound). Disclosure to the relevant authorities may be required in the event it is compelled by law or court order, a participant discloses any information that raises a serious concern about the safety of the participant, the safety of other persons that may be endangered by the participant's behaviour or the health, safety or welfare of any children or vulnerable adults. Unless there was an immediate, compelling and urgent need to disclose, the researcher would consult with Professor Nichola Rumsey before any such disclosure is made.

**7. Please describe how you will store data collected in the course of your research and maintain data protection.**

All electronic data will be stored in a secure location (such as personal drives on the password protected UWE system) that can only be accessed by the researcher. Paper documents that contain identifying information (including the completed consent forms which will form the only link between participant's identifiable information and the data relating to them) will be stored in a locked filing cabinet in a room on the University premises occupied exclusively by CAR staff, PhD students and occasionally visitors to CAR or MSc placement students. The room in which the consent forms will be stored is locked when it is not occupied.

The audio recordings of the interviews will be stored in a secure location (such as personal drives on the password protected UWE system) that can only be accessed by the researcher and will be deleted once the analysis of the full data set is complete. The remaining study data (interview transcripts) and consent forms will be deleted / destroyed five years after the analysis of the research is complete.

Electronic copies of all e-mail correspondence related to potential participants and participants will be retained by the researcher in his UWE staff e-mail account and stored in a dedicated folder. All emails will be deleted once data collection has ceased.

Professor Nichola Rumsey will be provided with the information necessary to access the above data so that it may be accessed by someone other than the researcher in case this is necessary in the event of any unforeseen circumstances.

**8. What risks (eg physical, psychological, social, legal or economic), if any, do the participants face in taking part in this research and how will you overcome these risks?**

The study poses few physical, social, legal or economic risks to participants and the processes detailed in sections 5 to 7 will ensure that their confidentiality and anonymity are maintained. The remaining risk to participants is psychological in nature. The sensitive nature of the area being researched and the possibility of visible differences impacting negatively upon participants' well-being and experiences of intimate relationships combine to create a risk that participants experience some level of distress or discomfiture during the interviews. It is possible that this may be in response to discussing specific upsetting incidents (which may include rejection, the break down of relationships or even sexual abuse or harassment) or in response to more general feelings

and perceptions (such as being unattractive or being unloved).

In order to reduce this risk to participants a number of protective measures will be taken. The Participant Information Sheet informs participants that they are free to withdraw from the study and terminate the interview at any time and that they are not obliged to answer any question or talk about any issue that they do not want to discuss. The researcher will be sensitive to signs of distress and will take steps such as reminding participants that they do not have to talk about anything that is distressing them, offering the participant a break and even discontinuing the interview if distress is apparent. The researcher's experience as a listening volunteer and shift leader with the Samaritans as well as previous research with NHS cancer patients means that the researcher is well placed and well prepared for any such situation should one arise. At all times the researcher will adopt a professional but sensitive, understanding and non-judgemental tone and manner in order to ensure the researcher does not cause participants any upset. The incident, event or feelings causing distress will be acknowledged, the participant will be given the chance to say as much or as little about them as they wish and will not be rushed, pressurised or hurried in any way. The interview will proceed only when and if the participant is ready and happy to continue.

In addition to handling any such distress or disclosure in a sensitive manner, the researcher will ensure that contact details for relevant organisations such as the Samaritans, Changing Faces and Mind are available and will offer these to any participants that exhibit signs of distress. Likewise, participants exhibiting signs of distress will be offered the details of the NHS Outlook service and may wish to consider approaching their GP for a referral to that service. As part of a post interview debriefing session participants will be asked how they are feeling and how they found the experience of the interview. If the participant indicates any level of distress or discomfort then the researcher will remain sensitive to their emotional state and the participant will be offered the details of these organisations.

Whilst this risk of participant distress must not be discounted and will be taken seriously, there is no suggestion in the existing literature (e.g. detailed in section 1) that research concerned with the intersection of visible difference and intimacy has been experienced by participants as distressing or upsetting. Likewise, the researcher is not aware of distress being caused to participants through their participation in other (non-intimacy focussed) visible difference research. It is therefore considered relatively unlikely that this risk will materialise and the researcher is confident in his ability to effectively and sensitively manage the situation should any participant exhibit signs of distress.

**9 Are there any potential risks to researchers and any other people impacted by this study as a consequence of undertaking this proposal that are greater than those encountered in normal day to day life?**

There are no anticipated risks to any person other than the researcher and the research participants (as discussed in section 8 above).

The risks to the researcher may be categorised into physical risks and risks to the researcher's psychological well-being.

Physical risks are considered unlikely to materialise but the researcher will remain alive to

the possibility when conducting face-to-face interviews, whether these occur on UWE, public or private property. The researcher will adopt sensible measures such as ensuring a colleague (depending on availability this will be Professor Nichola Rumsey or another member of CAR) knows when and where any such interviews are taking place and contacting the colleague by mobile phone to confirm the arrangements prior to the interview and immediately after the interview. If the colleague has not heard from the interviewer they will phone the interviewer approximately ninety minutes after the start time of the interview to ensure there are no unusual circumstances. The UWE Safety of Social Researchers guidelines will be applied and participants will only be interviewed in their home if the participant is unable to be interviewed elsewhere (for example due to social anxiety). Otherwise the interviews will be conducted at UWE or at a convenient local location for the participant. The recruitment methods envisaged (section 4) anticipates prior telephone and/or e-mail contact and this can be used to make some assessment of the participant and their circumstances as the UWE guidelines suggest. The researcher is experienced in offering a listening service to those in distress (both on the phone and in person) from his three years as a Samaritans volunteer. The training received for that role means that the researcher is alert to safety considerations such as choosing a seat near to an exit, ensuring there is sufficient physical and interpersonal space between the researcher and the participant and asking the participant in advance whether there will be any other persons (or pets) present at the location.

That previous listening experience also means that the researcher is very familiar with listening to people talking about distressing life stories and circumstances, both in person and on the phone. As such, the researcher is appropriately prepared and emotionally equipped to deal with participant distress and to not become overly personally distressed should any participant recount unhappy memories or dissatisfaction with any element of their life. Despite this, interviews will be scheduled sensibly so that no undue emotional burden is placed upon the researcher. In the unlikely event of the researcher experiencing distress or a strong emotional reaction to conducting the research, the experience and inter-personal skills of Professor Nichola Rumsey will be drawn on and a full debriefing undertaken.

#### **10 How will the results of the research be reported and disseminated?**

*(Select all that apply)*

- ☒ **Peer reviewed journal**
- ☒ **Conference presentation**
- ☐ **Internal report**
- ☒ **Dissertation/Thesis**
- ☐ **Other publication**
- ☒ **Written feedback to research participants (those that request it and in aggregate form)**

<input type="checkbox"/> <b>Presentation to participants or relevant community groups</b>  <input type="checkbox"/> <b>Other (Please specify below)</b>
<p><b>11 Are there any other ethical issues that have not been addressed which you would wish to bring to the attention of the Faculty and/or University Research Ethics Committee?</b></p> <p>The participant information sheet clearly states that the interviews are for the purposes of research and do not constitute any kind of therapeutic intervention or treatment and the researcher is not qualified to offer this. This has been made explicit to ensure that participants are not accidentally misled, the nature of the interaction is understood by participants and their expectations of the potential benefits of participating are realistic.</p> <p>The majority of this application focusses on the possibility of participant and/or researcher distress and therefore appears to assume that those who have a visible difference may experience difficulty in their intimate relationships. This is a construct of the application processes and occurs because of the nature of the questions asked which understandably focus on potential harm and thus encourage the applicant to imagine scenarios that may be distressing for participants so that they can be prepared and protect participants well-being. One of the aims of the research, however, is to consider participants' positive experiences and to examine what participants believe facilitated these. Similarly any beneficial impact of visible differences upon intimacy, such as disclosure of a condition acting as a screening tool for potential partners (Mathias and Harcourt, 2014) or a partner's positive reaction increasing perceived levels of trust or commitment (Hannah et al 1992) will also be discussed and form part of the analysis. There will thus be some focus on positive experiences, positive adjustment and the facilitative factors as Clarke (1999) has called for. This will serve to avoid the potentially unethical solely negative focus and pathologising of visible differences that Egan, Harcourt and Rumsey (2011) warn of.</p>

### **Checklist**

*Please complete before submitting the form.*

	Yes/No
<b>Is a copy of the research proposal attached?</b>	<b>n/a</b>
<b>Have you explained how you will select the participants?</b>	<b>Yes</b>
<b>Have you described the ethical issues related to the well-being of participants?</b>	<b>Yes</b>
<b>Have you considered health and safety issues for the participants and researchers?</b>	<b>Yes</b>
<b>Have you included details of data protection including data storage?</b>	<b>Yes</b>

Have you described fully how you will maintain confidentiality?	Yes
Is a participant consent form attached?	Yes
Is a participant information sheet attached?	Yes
Is a copy of your questionnaire/topic guide attached?	Yes
Where applicable, is evidence of a current DBS (formerly CRB) check attached?	Yes
Is a Risk Assessment form attached? (HAS only)	Yes

### Declaration

The information contained in this application, including any accompanying information, is to the best of my knowledge, complete and correct. I have attempted to identify all risks related to the research that may arise in conducting this research and acknowledge my obligations and the right of the participants.

Principal Investigator name	Nicholas David Sharratt
Signature	NDS
Date	31/03/2015
Supervisor or module leader name (where appropriate)	Professor Nichola Rumsey
Signature	NR
Date	31/03/2015

The signed form should be emailed to Committee Services: [researchethics@uwe.ac.uk](mailto:researchethics@uwe.ac.uk) and email copied to the Supervisor/Director of Studies where applicable.

**Appendix A5: Qualitative Study: University of the West of England Faculty of  
Health and Applied Sciences: Faculty Research Ethics Committee Approval  
Letter**



**Faculty of Health &  
Applied  
Sciences  
Glenside Campus  
Blackberry Hill  
Stapleton  
Bristol BS16 1DD**

**Tel: 0117 328 1170**

UWE REC REF No: HAS/15/03/132

5<sup>th</sup> May 2015

Nicholas Sharratt  
Room 2L13  
Frenchay Campus  
UWE

Dear Nicholas

**Application title: Exploring Experiences of Visible Difference, Intimacy and Intimate Relationship**

Your ethics application was considered by the Faculty Research Ethics Committee and, based on the information provided, has been given ethical approval to proceed.

You must notify the committee in advance if you wish to make any significant amendments to the original application using the amendment form at  
<http://www1.uwe.ac.uk/hls/research/researchethicsandgovernance.aspx>

Please note that any information sheets and consent forms should have the UWE logo.

Further guidance is available on the web:

<http://www1.uwe.ac.uk/aboutus/departmentsandservices/professionalservices/marketingandcommunications/resources.aspx>

The following standard conditions also apply to all research given ethical approval by a UWE Research Ethics Committee:

1. You must notify the relevant UWE Research Ethics Committee in advance if you wish to make significant amendments to the original application: these include any changes to the study protocol which have an ethical dimension. Please note that any changes approved by an external research ethics committee must also be communicated to the relevant UWE committee.
2. You must notify the University Research Ethics Committee if you terminate your research before completion;

3. You must notify the University Research Ethics Committee if there are any serious events or developments in the research that have an ethical dimension.

Please note: The UREC is required to monitor and audit the ethical conduct of research involving human participants, data and tissue conducted by academic staff, students and researchers. Your project may be selected for audit from the research projects submitted to and approved by the UREC and its committees.

We wish you well with your research.

Yours sincerely

Dr Julie Woodley  
Chair  
Faculty Research Ethics Committee

*c.c. Nichola Rumsey*

## Appendix A6: Qualitative Study: University of the West of England General Risk Assessment Form



University of the  
West of England

### GENERAL RISK ASSESSMENT FORM

Ref:

HAS/15/03/132

<b>Describe the activity being assessed:</b>  <b>Interview study of participants to occur remotely (via phone / skype) and / or face to face interactions (on UWE premises, venues in the participant's local community, the participant's home)</b>	<b>Assessed by:</b>  Nicholas Sharratt	<b>Endorsed by:</b>  Professor Nichola Rumsey
<b>Who might be harmed: Researcher, Participants</b>  <b>How many exposed to risk:</b> <span style="border: 1px solid black; padding: 2px;">Approx 30</span>	<b>Date of Assessment:</b>  19/03/2015	<b>Review date(s):</b>  19/03/16 if project is ongoing, it's likely to be under 12 months in duration

Hazards Identified (state the potential harm)	Existing Control Measures	S	L	Risk Level	Additional Control Measures	S	L	Risk Level	By whom and by when	Date completed
(Researcher- human/ behavioural factors) stress, discomfort and distress due to the sensitive nature and content of the interview data	Researcher's experience in listening to others talk of distress  Opportunity to debrief with colleagues	2	1	2						
(Researcher- human/ behavioural factors) stress, discomfort and distress due	Interviews will necessarily be conducted in private. Where this occurs in a participant's home and, to a lesser extent on other premises	3	1	3						

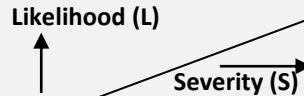
to the possibility of a participant accusing the researcher of any inappropriate or offensive behaviour during the interview session	and even on-line or over the phone, this risk may subsist. Interviews will be audibly recorded but the recording will cover only the substantive interview. The researcher will maintain an appropriate physical and interpersonal distance and not act in a way that can reasonably be interpreted as aggressive, offensive or suggestive									
(Participant- human/ behavioural factors) stress, discomfort and distress due to the sensitive nature and content of the interview data	<p>Prior to the study participants will be informed about the general issues and topics covered in the research - it is likely that those participants who may be at a heightened risk of distress/ detrimental effects will choose not to participate.</p> <p>Participant’s right to withdraw from the study at any time and for any reason will be emphasized at the beginning of the study. Similarly, participants will be informed that they do not have to talk about any particular issue or to answer any particular question. It is up to the individual participant to make an informed choice as to whether they carry on or stop the study.</p> <p>The researcher fully subscribes to the participants’ right to withdraw from the study at any time and to talk only about matters that they are comfortable talking about. No pressure will be exerted on participants to the contrary.</p>	3	2	6	Participants will be asked how they are and how they found the experience as part of a post interview debriefing session. Those who express or indicate distress will be offered a list of sources of support and links to relevant organisations and charities will be available to participants and details of further, condition specific, organisations and charities can be provided	2	2	4	By the researcher as and when participant s request this informatio n	On an ongoing basis

					upon request.					
Human behaviour factors: a participant becomes verbally or physically aggressive towards the researcher	<p>The researcher will have e-mail and/or phone contact with the participant prior to meeting them and so can make some assessment of the likelihood of this occurring. Any concerns will be discussed with experienced colleagues and a decision made about whether to proceed, rearrange the format or location of an interview or cancel the interview</p> <p>Interviews will be conducted in person at the participant's home only where this is the preferred choice of the participant/ It is likely that most interviews will be conducted remotely or on UWE or neutral premises, thus reducing the researcher's exposure to risk</p> <p>The researcher will ensure colleagues are aware of where and when the interviews are taking place and will make arrangements for phone contact to occur immediately before and after the interviews (face to face interviews only)</p> <p>When interviewing at a participant's home, the interviewer will ask in advance whether any other persons will be present and will be alert to any discrepancies (face to face interviews only)</p> <p>The researcher will maintain an appropriate physical and interpersonal distance from the</p>	3	1	3						

	<p>participant</p> <p>The researcher will be aware of the physical environment and, for example, choose to sit near to an exit</p> <p>The researcher will have the opportunity to debrief with colleagues</p>									
Animals: possibility of animals being present at interview site (relevant primarily for interviews conducted at a participant's home)	<p>The researcher will ask the participant in advance whether any animals or pets may be present, the living arrangements of the animals and will discuss any concerns with the participant. In the event the concerns are not addressed then a decision made about whether to proceed, rearrange the format or location of an interview or cancel the interview</p> <p>The interviewer has experience of ad is comfortable with most household animals and has no known allergies or phobias</p>	3	1	3						
Transport (traffic) and weather to and from interview venues (face to face interviews only)	<p>This carries the normal level of risk associated with travel and weather though the study may involve the researcher engaging in additional travel and will be minimised by checking travel arrangements in advance and before starting each journey</p>	4	1	4						

Fires/flames	<p>The researcher will familiarise himself and (when conducting face to face interviews) participants with locations (other than participants home) fire evacuation procedures, such as tone/pitch of fire bell (or fire evacuation alert), locating the nearest fire exits in each room used, location of meeting points, signing in/out of the facility</p> <p>In interviews in participants' homes the researcher will remain aware of the route to the exits</p>	4	1	4						
Slip, trip or fall	<p>The researcher will remain aware of and alert to the physical environment and any such hazards. This is especially pertinent for any interviews conducted away from UWE premises and where UWE has no control over the environment</p>	2	2	4						

**RISK MATRIX: (To generate the risk level).**

Very likely 5	5	10	15	20	25
Likely 4	4	8	12	16	20
Possible 3	3	6	9	12	15
Unlikely 2	2	4	6	8	10
Extremely unlikely 1	1	2	3	4	5
Likelihood (L)  Severity (S)	Minor injury – No first aid treatment required 1	Minor injury – Requires First Aid Treatment 2	Injury - requires GP treatment or Hospital attendance 3	Major Injury 4	Fatality 5

**ACTION LEVEL: (To identify what action needs to be taken).**

POINTS:	RISK LEVEL:	ACTION:
1 – 2	NEGLIGIBLE	No further action is necessary.
3 – 5	TOLERABLE	Where possible, reduce the risk further
6 - 12	MODERATE	Additional control measures are required
15 – 16	HIGH	Immediate action is necessary
20 - 25	INTOLERABLE	Stop the activity/ do not start the activity

## **Appendix A7a: Summary of Themes Sent to Participants**

### **Summary of Themes**

The interview study entitled “Exploring Experiences of Visible Difference, Intimacy and Intimate Relationships” involved the researcher (Nick Sharratt) interviewing twenty-two participants who had experience of a variety of appearance altering conditions and visible differences.

#### **Participants**

The visible differences and appearance altering conditions that participants had experience of included: Cleft Lip, Clef Lip and Palate, Alopecia, Psoriasis, Breast Cancer related appearance changes, Ankylosing Spondylitis, Facial Birthmark, Facial Scarring, Ichthyosis, Facial Palsy and one participant with multiple aetiologies (Facial Palsy and Breast Cancer related appearance changes).

#### **Themes**

The themes summarised below have been drawn from across the interviews conducted and they represent areas of commonality and agreement between the accounts. It is important to acknowledge that not every theme was represented in every interview and some participants’ individual experiences may have differed from those presented here. Similarly, some participants did not believe that their visible difference had impacted upon them as a person or upon their intimate life. This will be reflected upon and discussed more fully in future publications related to this study.

The following themes were identified from the interviews:

#### **1) Looking At My Life**

This overarching theme captures participant’s thoughts about how their appearance may have impacted upon them as a person and upon their life

##### **a) Me, My Appearance and I**

Appearance was felt to be linked with personal identity and to have impacted upon participants’ traits and characteristics in a number of ways. These were considered both negative or detrimental (i.e. reduced confidence, increased self-consciousness and anxiety) and, to a lesser extent, positive or beneficial (determination, strength, resilience, openness and acceptance).

### **b) Hiding Away**

Many participants described behaviours adopted in order to reduce or minimise the visibility of their difference to others and this seemed connected to a desire for normality, to blend in and to be treated and viewed like any other person. These behaviours extended to the disguise or concealment of difference (i.e. via the use of clothing, hairpieces, make up) and, in response to feelings of fear and anxiety, the avoidance of activities (i.e. swimming) and social contexts (i.e. pubs).

### **c) This Lonely Planet**

There was a feeling that it can be very difficult for those that do not have a visible difference to fully understand the impact it may have on a person's thoughts, feelings and life. This extended to the healthcare professions and the lack of professional support. When talking about what organised support may be most valuable, participants predominantly suggested that peer-to-peer support and expert patient led groups would be most likely to be beneficial to those with appearance concerns and that information should be provided to those who may benefit in a proactive and timely manner from these groups or from other forms of support.

## **2) Appearance In a Social Context**

Appearance was also considered to be a social phenomenon both in terms of how we, as a society, assign importance to appearance and in terms of the everyday experience of living with a visible difference.

### **a) Appearance Is Important**

Within this sub-theme participants spoke about how and why appearance is important as a projection of the self into the world and how it was felt that many people make judgements based upon how someone looks. This 'appearance is important' idea was supplemented by the contentions that this was at least partially attributable to the influence of the media and, due to varying social pressure, was especially so for females. There were caveats, however, and appearance was not considered to be so important where people have had the opportunity to learn otherwise nor, to the participants themselves or their close family and friends.

### **b) Comparative Normality**

It was evident that a number of participants made or make appearance based comparisons with real or hypothetical others. Often these were to people who may be considered less fortunate in having a more severe or noticeable difference in their appearance in which case the idea of being lucky was often invoked. Sometimes, however, comparisons were also made with those who were portrayed as being more fortunate. The focus tended to be on physical severity of a condition in making these comparisons though some other matters were mentioned (i.e. the ability to conceal or disguise, treatment and support experiences)

### **c) Being Public Property**

The presence of a visible difference led to participants being aware of other people's intrusive stares, prolonged glances and uninvited comments and questions. The comments responses were felt to negate participants' right to privacy and position them as public property. The comments from others often associated differences in appearance with illness and disease (sometimes incorrectly) and, sometimes, invoked a level of stigma. Participants spoke about how they manage the public reactions of others. Some identified the propensity of others to look and judge as being natural, though still upsetting and/or uncomfortable. A few participants considered the possibility that they had become hypersensitive to the stares and glances of others and questioned whether their visible difference was always the actual target of these perceived looks.

## **3) Appearance Attracts and Detracts**

This theme reflects the belief, expressed explicitly by some participants, that seeking a relationship is one of (or even the) biggest issue for those with visible differences. Appearance was presented as being of fundamental importance to attraction with the initiation and initial stages of a relationships generally being understood to be where the biggest challenges reside

### **a) We Are How We Look**

This highlights the perceived importance of physical appearance and initial impressions to attraction and how participants felt their visible difference may act as a barrier in this

process. The potential impact on participants' intimate lives was amplified by the doubt and uncertainty that some expressed in connection with more positive or even with neutral reactions. Several participants expressed the idea that in order to overcome these issues the most viable way into a relationship was via a route that included being friends with the potential partner first, building trust and understanding before progressing to a more intimate relationship.

#### **b) The Discounted Self**

Many participants, including those in intimate relationships, seemed to in some way discount themselves as viable intimate partners. This stemmed from a sense of being deficient in some way and not deserving the interest and attention of another. This may have resulted from any combination of internalised societal ideals, the negative reactions and comments of others (including some potential partners and some ex-partners) and participants own feelings about themselves. This idea of being (or being judged by others as) some way deficient was, amongst female participants, of particular relevance to those whose difference was to feminine or sexualised areas of the body (i.e. hair, breasts). Other participants discussed how it may be possible to compensate for the 'deficit' a visible difference may create (i.e. via education, force of personality, financial wealth, sporting prowess)

This discounting of the self was also apparent in participants expressing their gratitude, or luck, at having a caring partner or having romantic interest expressed in them. This suggests that for some, such happy circumstances were attributable to good fortune or chance rather than being deserved. An alternative but related view is that appearance ideals are so ingrained and important to our society that it is rare to find someone who can look past a visible difference to the 'real' person. A suggestion also emerged that defining oneself as deficient and/or lucky may have contributed to the acceptance of sub-optimal previous relationships for a small number of participants and a feeling that there is a more limited choice of potential partners as a result of their appearance.

#### **4) Physicality and Physical Reality**

This theme is devoted to the physical consequences of a visible difference. The associated self-care and treatment routines are acknowledged together with the relational and interpersonal consequences related to disclosure, physical intimacy and inheritable conditions.

#### **a) The Disclosure Dilemma**

Of relevance to those whose difference is not ordinarily visible or who conceal or disguise their visible difference were feelings of real uncertainty and doubt about how and when to tell or show a new partner. This was particularly salient for those seeking a relationship at the time of the study though those with a partner also reflected on historic disclosure. Uncertainty over the optimal time and (for those utilising them) how to present on internet dating site profiles, nervousness about the reaction of the other, feelings of being in some way dishonest until the point of disclosure and the idea that this is an additional hurdle to overcome in the difficult pursuit of initiating a new relationship were characteristic of the concerns experienced. Previous experiences of disclosure were not typified by overtly negative reactions from others but whilst some participants could recount supportive responses from others and reflect on the experience as a positive intimate exchange in its own right, others reported a definite cooling of interest often masked behind a façade of acceptance.

#### **b) Invading Physical Intimacy**

Just over half of the participants talked about how they believed their visible difference impacted to some degree upon sex and physical intimacy. This occurred in three main ways. The first was to act to reduce participants' desire to engage in physical intimacy or in specific acts of intimacy, primarily as a result of the participant's feelings of unattractiveness or discomfiture around their difference. In some instances this resulted in prolonged periods of sexual inactivity within existing relationships. Secondly, a relatively small number of participants described unease at being seen (or at the area affected by a difference being seen) by their partner. As such, strategies were employed to avoid this occurrence (i.e. wearing clothes, covering the self with bedclothes). Finally, appearance concerns were understood to act to reduce some participants' sexual enjoyment and pleasure and detract from their ability to experience and 'be in the moment.'

#### **c) Selfish Genes**

Where a visible difference was related to a congenital or inheritable condition, some spoke about considering the possibility that their children may acquire a visible difference. Whilst this was rarely the deciding factor in whether or not to have children, this possibility provoked some anxiety as participants understood the potential impact this might have upon their children's lives. Participants also conveyed a sense of guilt or potential guilt in relation to this possibility. It was, however, also believed that the participants' children (actual or anticipated) and the participants themselves were more open, understanding, accepting and less prejudicial than they may otherwise have been.

## **5) Delineating and Defining Relationships**

Nurturing intimate relationships were highly valued and viewed as exerting, or potentially exerting, a positive influence upon participants' lives and, in some cases, even lessening the personal impact that their difference would otherwise be having. Conversely, the cessation of less positive relationships was also discussed in similar terms by a small number of participants. Visible differences were also understood to be capable of influencing relationships in a number of ways.

### **a) Testing the Water**

The reaction and sensitivity of a partner to a visible difference was understood as saying something about the nature of that other person and their suitability as a partner. This could be understood as a filtering process. In addition, conceptualising these reactions as a test of the other people involved may represent a shift of focus from self-focussed attention concentrating on the participant and their difference to an assessment of the suitability of the other person as a potential partner.

### **b) Treasure, Enrichment and Fortification**

The support that a caring partner is capable of providing and the potential impact on participants as people is reflected in this theme despite some saying that they had never discussed their appearance or its impact upon their intimate lives with their partner. The acceptance of a visible difference was considered to indicate that the relationship had achieved a level of depth and legitimacy and also to contribute to the likelihood that it would endure. The trust and acceptance that this requires was seen as building something strong and lasting and was occasionally contrasted with relationships that may be built on

more superficial grounds. Some participants attributed positive elements of their personality to their experiences of overcoming their difference and the prejudices of others and argued that they and their relationship may have been different and perhaps weaker if they had not had these experiences.

In discussing potential support needs, some participants conveyed the view that healthcare professionals seemed unwilling or unable to discuss intimacy concerns. A couple of participants even felt that this was considered entirely outside the remit of the health service and it was therefore not communicated as a legitimate topic for a clinical discussion. In line with other discussions about support needs, participants felt that peer-to-peer and expert led patient groups would be the most appropriate way of providing support when required.

## **Appendix A7b: Qualitative Study: Health Psychology Update Article**

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This is a pre-publication version of the following article:

Sharratt, N. D., Jenkinson, E., Moss, T., Clarke, A., Rumsey, N., & The VTCT Foundation

Research Team at the Centre for Appearance Research. "Experiences of Living with Visible Difference: Individual and Social Reflections" *Health Psychology Update*, Volume 28 Issue 2

### **Experiences of Living with Visible Difference: Individual and Social Reflections**

Nicholas David Sharratt, Dr Elizabeth Jenkinson, Dr Timothy Moss, Dr Alexandra Clarke, Professor Nichola Rumsey, The VTCT Foundation Research Team at the Centre for Appearance Research

#### **Abstract**

Many health conditions impact upon an individual's appearance and result in an altered appearance ("visible difference"). The presence of visible difference is associated with a variety of psychosocial difficulties and challenges, yet calls for an integrated theory of adjustment remain largely unanswered. This qualitative research, conducted in the United Kingdom, drew upon 22 interviews conducted with participants who had a variety of visible differences. It examined their experiences and reflections related to their difference and the impact that their visible difference had upon their lives. A thematic analysis produced two themes. The first of which was predominantly concerned with the impact of visible difference upon the individual whilst the second captured the inherently social nature of appearance and appearance based judgements. The analysis is considered in light of the contention that an integrated theory of adjustment to visible difference is required and participants' experiences with healthcare professionals and the implications for those

providing care are introduced.

## **Introduction**

A wide variety of health conditions may impact the appearance of the individual. An altered appearance or disfigurement (a 'visible difference') may result from congenital or genetic conditions, disease processes, and the consequences of treatment or acute traumatic events (Kent & Thompson, 2002). Visible difference is of itself relevant to health and well-being and thus of legitimate concern to the healthcare profession. Its presence is associated with a broad range of psychosocial challenges in a significant minority of those with a difference (Harcourt & Rumsey, 2008). These include raised anxiety levels, depression, social anxiety, social avoidance, and reduced quality of life (Rumsey, Clarke, & White, 2003). Visible difference may evoke negative reactions from others (Thompson & Kent, 2001), stigmatisation (Goffman, 2000), and contribute to lowered self-perceptions and difficult social interactions via a spiral of negative emotions, maladaptive thought processes, unfavourable self-perceptions, and unfavourable behavioural patterns (Rumsey & Harcourt, 2004).

These psychosocial difficulties are, however, not well predicted by the specific type or nature of the difference or its size (Rumsey et al., 2003; Rumsey, Clarke, White, Wyn-Williams, & Garlick, 2004). Neither is there a linear relationship between objective measures of severity and distress, with an individual's subjective evaluation of their difference being more strongly related to psychological adjustment (Moss, 2005; Ong et al., 2007).

Despite the recognition that visible difference may be accompanied by psychological distress and challenging social interactions, a complete understanding of the mechanisms through which these occur remains elusive. Kent (2000) has argued for an integrated theory, evidencing the utility and applicability of four psychological models of visible difference (a social anxiety model, the sociological models of stigma, social skills training and

the body image schema model) to the experiences of those with vitiligo. Such integration has not yet fully occurred.

Furthermore, there exists a rather limited body of qualitative research focussed on exploring adult's experiences of visible difference as opposed to that focussed upon a specific condition. For example, like Kent (2000), Thompson, Clarke, Newell, Gawkrödger, and ARC (2010) drew on the experiences of those with vitiligo. Other studies have concentrated on the experiences of those with specific conditions such as epidermolysis bullosa (Dures, Morris, Gleeson, & Rumsey, 2011) and cleft lip and/or palate (Stock, Feragen, & Rumsey, 2015). Qualitative research which has focussed upon visible difference has not examined the comments of Kent (2000) and has had a specific focus such as positive adjustment (Egan, Harcourt, & Rumsey, 2011), managing intrusive reactions (Thompson & Broom, 2009), or the romantic experiences of adolescents (Griffiths, Williamson, & Rumsey, 2012) rather than examining lived experiences of visible difference more broadly.

The current research therefore aimed to explore the appearance related experiences and reflections of participants with a variety of visible differences and examine any perceived impact of their difference upon their life. It was also intended that the findings be used in order to consider the contention of Kent (2000) that an integrated theory of adjustment to visible difference is required.

## **Materials and Methods**

### ***Method***

Participants' personal experiences were explored through the medium of semi-structured individual interviews. The present data form part of a larger data set collected during interviews exploring visible differences and intimate, romantic relationships, reported in (Sharratt, Jenkinson, Moss, Clarke, & Rumsey, 2018) and which were intended to be used in the development of a research measurement tool or scale focussed upon this topic.

The research received ethical approval from the University of the West of England faculty research ethics committee. The interviews were largely composed of two distinct

sections with the first part of the interview considering participants' feelings and experiences of visible difference generally and the second part focussing on romantic relationships. The section of the interview guide that related to participants' more general feelings and experiences are included in Table 1. As the interviews were semi-structured in nature, the questions were deployed flexibly and responsively.

Table 1. *Semi-Structured Interview Guide Questions*

Questions
Could you tell me a little about the nature of your visible difference?
How important do you think appearance is in general, does it matter what we look like?
How do you feel about your own appearance?
Speaking generally, would you be able to describe any impact that your appearance has had upon your day to day life?
Could you tell me about any changes over time in how you feel about your appearance and any impact it has on your life?

Participants were offered a choice of whether to participate via the phone, in person, or by means of an internet mediated video service. This choice ensured consistency across the data set as all data were produced via contemporaneous, immediate verbal exchanges. This choice was offered in recognition of the arguments that phone interviews can produce high quality data, can be appropriate for sensitive topics, and as concerns about their utility have little evidential basis (Novick, 2008). Interviews were performed by the first author, digitally recorded, and transcribed verbatim.

### ***Participants***

The study was advertised by 17 relevant support groups and charities, through the social media of the research centre in which the first author is based, and via a University press release. Twenty-two participants were interviewed. This included 16 women and six men. Participants were aged between 25 and 64 with an average age of 43 years. Six were single and the other 16 were in a relationship or married. Interviews lasted an average of 65 minutes. Of the 22 participants, 15 chose to be interviewed over the phone, five in person and two via skype. To protect participant anonymity, pseudonyms have been used in this report.

Eight participants had a condition that had been present since birth, the remaining 14 had acquired their visible difference at a subsequent stage of life. Twelve participants indicated that their difference was ordinarily visible to other people, the other 10 participants did not believe this to be so. Eight participants had a condition they described as congenital or genetic, whilst the remaining 14 had acquired their difference through injury, illness, or disease. The participants' visible differences were: Alopecia (five participants), Ankylosing Spondylitis (one), Breast Cancer-related Scarring (two), Cleft Lip and/or Palate ('cleft') (six), Facial Birthmark (one), Facial Palsy (one), Facial Palsy and Breast Cancer-related Scarring (one), Facial Scarring (one), Ichthyosis (one), and Psoriasis (three).

### ***Analysis***

The data were analysed via inductive thematic analysis following the six steps detailed by Braun and Clarke (2006, 2013) and as described in Sharratt et al. (2018). An inductive form of thematic analysis was employed as the data were focussed upon individual experiences and so an explicitly and primarily data-driven approach was considered appropriate, although the authors' personal experiences and knowledge of existing literature are acknowledged as being relevant to the performance of the research, including the analysis.

The eventual goal of the research programme, to devise a research tool, and the intention of utilising the data in order to interrogate the call of Kent (2000) for an integrated theory of visible difference, meant that the broader implications of the data would be considered. The Pragmatism of Morgan (2007, 2014) was therefore an appropriate paradigm from which to conduct this research in recognition that the transferability of the findings would be considered, the abductive nature of the analysis, and the intersubjectivity inherent in examining participants' unique interpretations of, and reflections upon, their experiences. The theoretical flexibility afforded by thematic analysis (Braun & Clarke, 2006) meant that it was appropriate for this research.

In a process which further reflected the intersubjectivity (Morgan, 2007) that characterised this research, the analysis was conducted by the lead author and verified

through discussion and consultation with the co-authors until consensus was reached, described in Sharratt et al. (2018).

## **Results**

The analysis resulted in the generation of five main themes each with several sub-themes. Three of the five themes were specific to intimacy and romantic relationships and are reported by Sharratt et al. (2018). The two remaining themes were concerned with the broader impact of visible difference upon participants and are reported here. The first, 'Personal Reflections on Looking Different' was concerned with the individual impact of visible difference upon participants. In contrast 'Our Socially Situated Appearance' focussed upon the belief that appearance is an intensely social phenomena, shaping interactions with others. These two themes, their associated sub-themes, and example codes are illustrated in Table 2.

Table 2. *Themes, Subthemes, and Example Codes*

Theme	Subtheme	Example codes
Personal Reflections on Looking Different	Becoming one with difference	Reduced confidence
		Positive growth
	Hiding away	Cover difference
		Avoidance
	This lonely planet	Others not understand
		Lack support
Our Socially Situated Appearance	Appearance as a projection	First impressions
		Judgement
	Being public property	Intrusion
		Assumptions
	Searching for comparative normality	Downward comparisons
		Upward comparisons

### ***Personal Reflections on Looking Different***

This theme detailed participants' understanding of the primarily negative individual and personal consequences of living with a visible difference. These included the perceived impact upon participants' personal characteristics, the behaviours that they adopted in connection with their appearance, and the availability of appropriate support. The focus was very much upon the impact of appearance at the level of the individual. This theme

contained three sub-themes. First, 'Becoming One with Difference' conveys participants' understanding that their personal identity and characteristics have been influenced by the presence of a visible difference. Some of the sentiments expressed in this sub-theme were offered as explanations for various avoidant behaviours that were contained within the second sub-theme, 'Hiding Away.' The final sub-theme 'This Lonely Planet' describes the sense of isolation that participants experienced and the tendency of family, friends and professionals to underestimate the impact of visible difference. The experience of effective support was the exception rather than the norm.

***Becoming one with difference.*** Participants explained that they believed their difference to have affected their personal traits and attributes in a number of ways. In the main, these impacts were experienced as detrimental and included reductions in confidence and increased self-consciousness:

I am quite self-conscious and I am quite sensitive. I can take offence quite easily. I do look for trouble. It's definitely affected me. (Pauline, Ichthyosis)

Several participants discussed how their difference had compromised their identity or sense of self. This appeared particularly pertinent where the difference was acquired and, prior to this acquisition, appearance had formed a significant part of their identity:

My confidence has taken a massive blow, particularly... I was known for "Oh [Ruth]'s got long blonde hair" and then suddenly I had nothing... without it you do sort of feel lost. (Ruth, Alopecia)

A number of participants considered that these effects diminished as they aged and learned to accept their appearance. Furthermore, a minority argued that the adversity they

had to contend with in connection with their difference fostered positive growth, determination and resilience:

If I wasn't born with a cleft lip and palate I wouldn't have the confidence or the determination that I have now. (Luke, Cleft)

***Hiding away.*** This sub-theme portrayed behaviours that participants adopted in order to reduce or minimise the visibility of their difference and present themselves as 'normal'. This was achieved through the strategic use of clothing, make-up, hair and hairpieces, facial expressions, and body language designed to exert control over the external visibility of their difference. This could involve considerable financial expense, time, inconvenience, or discomfort:

I'll still get up and put make-up on before we go outside and climb and I even think to myself "this is ridiculous" and a waste of time and money but I still do.  
(Chloe, Facial Birthmark)

Participants understood that they were motivated by the desire to avoid others seeing their difference, despite some suggestion that the reality was not as hurtful or damaging as initially feared:

I forced myself... "right, I'm going to do this, I'm going to go to the shops on my own and I've got to do it." Although I was sweating and I was a bit nervous... and sort of like no-one looked at me, barely took any notice, so I felt better for that.  
(Valerie, Facial Palsy and Breast Cancer)

Beyond this concealment of difference, participants also communicated avoidant behaviour and their withdrawal from social situations, interactions, events, locations,

situations, and activities. Commonly it was contexts that involve the expectation of scrutiny from others or the exposure of the body that were most problematic:

Walking to into a pub is my wors... along with high school, is the worst thing, not that I go to pubs and that's probably why I don't. (Charlotte, Cleft)

At its extreme this avoidant behaviour was debilitating and could exert a profound impact upon an individual's quality of life:

I'd say walk a mile in my shoes when I feel that I can't leave the house, which is kind of difficult to do really isn't it? (Eleanor, Psoriasis)

***This lonely planet.*** The final sub-theme represented participants' belief that it is extremely difficult for those that do not have a visible difference to fully understand the powerful impact it exerts upon their lives and therefore to offer empathetic support. Participants felt that those they were closest to had become accustomed to their difference to the extent that ongoing recognition of the challenges of difference from significant others in their lives was difficult to obtain:

I suppose maybe they think that I'm over it or it doesn't affect me or what does it matter... But you know, sometimes I just think sometimes people are a bit insensitive but... it'd be like talking about "oh my best friend's pregnant" or something when the other one's just had a miscarriage. (Elaine, Alopecia)

This extended into the provision of support by the healthcare profession, which was felt to be inadequate. Participants believed that the healthcare profession did not address the social and psychological consequences of visible difference, with the focus of care limited to the biomedical sphere:

I went for laser removal when I was 17 and then, at the same time, they sent me to a camouflage make-up specialist but it was always about removing it or hiding it. There was none, there was nothing about... support for living with it or accepting that it's there and not hiding it and not removing it... it was all very much like "It's not normal we'll get rid of it" rather than "It's fine" and ways of living with it. (Chloe, Facial Birthmark)

Likewise, a minority of participants detailed experiences of healthcare professionals overlooking or even explicitly dismissing their appearance concerns, with one participant feeling compelled to conceal her true motivation for having a prophylactic mastectomy of her healthy breast following Breast Cancer due to fear that her appearance concerns would be considered vain, superficial or '*shallow*':

I had to go and see a counsellor, talk to someone about why I wanted it, I couldn't really, I didn't feel comfortable talking to them about the aesthetics. I only really wanted this because I wanted to look normal. I had to speak more on the health side of it... but I just felt at the time that I couldn't really discuss it with anybody. (Jodie, Breast Cancer)

Participants felt it was important that psychological and social support was available to those with a visible difference. Possibly because of the perceived barriers in communicating with healthcare professionals and their experiences of a lack of empathetic support, participants voiced a preference for peer-to-peer and expert patient led support.

I think a peer group is probably definitely the strongest way to move on (Luke, Cleft)

A small minority of participants, however, recounted negative experiences of support groups, indicating that they could be emotionally traumatic as they may raise concerns about the future progress of a condition, involve judgment and comparisons being made by and about those present, and be particularly distressing:

(I) remember going to one support group meeting, which actually did really put me off because I turned up... and they'd all got their wigs on and it was just like "oh my God!" and I did come to realise I was further down the line than I thought I was and actually I had come to accept it because every time anyone spoke, they started crying. It was really just awful (Anna, Alopecia)

### **Our Socially Situated Appearance**

This theme emphasised the inherently social nature of appearance. Concerns about the negative reactions and judgements of others were understood to underpin some of the individual difficulties previously introduced. The 'Appearance as a Projection' sub-theme explains these concerns by positing that appearance is considered a projection of the self into the World and that a person's 'looks' say something fundamental about the individual concerned. One consequence of having an observable difference was to deny participants their privacy, discussed in 'Being Public Property.' The final sub-theme, 'Searching for Comparative Normality' describes the tendency of participants to make their own appearance based comparisons.

***Appearance as a projection.*** All participants considered that appearance was perceived by others to comprise a projection of the self and was subject to constant scrutiny. This was considered especially pertinent as initial impressions were formed and, crucially, was represented by participants as a process laden with value judgements:

You kind of assume someone who's fat is lazy, which is not always the case really. (Beth, Facial Scarring)

The tendency to look at others' differences and appraise someone on the basis of their appearance was explicitly considered to be normal or natural by some participants and so pervasive, ingrained and automatic that they themselves would also sometimes judge others in this way. Speaking about someone with a physical disability Michelle said:

When I very first met him I did presume that mentally, intellectually that he's not, sounds bloody awful doesn't it, not on the same sort of wavelength..... which now, saying it, sounds absolutely awful... I shouldn't just presume that for any reason his intellect or mental state is affected by it at all. (Michelle, Alopecia)

Participants considered this phenomena to be reinforced by media images and messages that dictate what constitutes a desirable appearance and exert pressure on individuals to conform to appearance ideals. This issue was considered especially pertinent and of more consequence for women than for men:

I feel sorrier for girls than blokes. Feel sorry for them all but the same thing about the way you look, I think it's more savage for a girl. (David, Cleft)

Although prone to making some evaluations about others based upon difference themselves, in the main participants often considered that they and their close friends and family as subsisting outside of an otherwise appearance obsessed world. Having a difference and having contact with someone else with a difference was thus believed to engender a more open, accepting attitude in participants and those around them:

My children being acceptable of people's differences. It's no big deal, they don't kind of do the whole pointing and staring. (Charlotte, Cleft)

***Being public property.*** Participants recounted experiences of intrusive stares, prolonged glances and uninvited comments and questions. This went beyond the private judgements that were believed to be made in the previous sub-theme, extending into behaviour:

If I do wear short sleeved stuff, short sleeved attire that's when a) I feel most ill at ease and b) when I'm more likely to catch criticism or, erm, horror or aversion from other people. (Austin, Psoriasis)

In cases in which a particular appearance is commonly associated with a specific health condition, such as women's hair loss and cancer, participants felt that others automatically assumed that they were ill. This belief appeared to offer permission to others to ignore normal social boundaries, overriding participants' right to privacy. This led Florence to feel compelled to engage in an uninvited conversation even though:

You don't want to talk to some stranger in the street, when other people are around, about what is or isn't wrong with you. You know, it's not, none of their business really. (Florence, Alopecia)

Whilst a small minority of participants said they did not mind being asked about their appearance, most who discussed this considered this an unwelcome invasion of their privacy and found it distressing. As privacy was implied by participants to be a basic right or politeness that individuals should extend to one another, the denial of it based on a socially stigmatised characteristic may be interpreted as discriminatory and a dehumanising experience.

***Searching for comparative normality.*** Whilst participants made a small number of upward comparisons in which they compared themselves to those they considered more fortunate, most appearance based comparisons were downward. Participants presented themselves as relatively lucky or unaffected:

My nose looked different... I mean it's still hooked now, it's not right but it could be a lot worse, put it that way. So that's another thing you think of as well. As a person I think "well it could be a lot worse." (Pete, Cleft)

These comparisons centred on the apparent severity of a difference and how far it distinguished someone from the norm. As such, they acted to normalise participants and potentially neutralise any threat or harm to their identity and self-esteem that was attached to their difference. They also acted to reproduce and reinforce the appearance norms and expectations of conformity that participants experienced as problematic.

## **Discussion**

These findings emphasise that participants with a visible difference considered appearance to be of central importance to their experiences of contemporary UK life. Their experiences of difference had exerted a substantial individual and social impact. Generally these impacts were considered negative, though there was some evidence of belief in positive adjustment and growth (Egan et al., 2011). The findings strongly allude to at least three of the four theories highlighted by Kent (2000). Dealing with each, the contention of Leary and Kowalsk (1995) that social anxiety reflects a universal concern about exclusion and rejection is evidenced throughout as participants' physical projection into the world was understood to be met with adverse judgements (Appearance as a Projection). It is conceivable that this contributed to reduced confidence (Becoming One with Difference)

and impression management via safety behaviours such as concealment and avoidance (Hiding Away) in an attempt to minimise the likelihood of exclusion and rejection.

Experiences of stigma (Goffman, 2000) were relevant within the sub-theme 'Being Public Property.' This included instances of both enacted and felt stigma (Scambler & Hopkins, 1986). Enacted stigma was experienced when a difference was visible to, and therefore known by, others who responded negatively to visible difference. Moreover, participants acknowledged that they may sometimes experience feelings of stigmatisation (felt stigma), even in the absence of enacted stigma (Hiding Away). The 'Hiding Away' sub-theme also constitutes evidence of an attempt at 'passing' (Goffman, 2000) as those whose stigmatised identity is concealable may attempt to pass themselves as non-stigmatised individuals.

Participants' beliefs that cultural influences such as the media provide messages that dictate and reinforce those aspects of appearance that are considered desirable and that such concerns are especially relevant for women (Appearance as a Projection), neatly encapsulate the body image disturbance model of Cash and Grant (1996). The particular concern over contexts involving bodily exposure and social scrutiny (Hiding Away) complete the alignment with Kent's (2000) description of this model.

Finally, the social skills model of Rumsey, Bull, and Gahagan (1986) and Partridge (1998) (both cited by Kent, 2000) may garner some, limited, support from this work. The potential for avoidant behaviour (Hiding Away) together with the obvious difficulty that intrusive reactions caused (Being Public Property) and the sense of isolation that was recounted (This Lonely Planet), suggest that some social interactions were experienced as challenging and that social skills training may therefore prove beneficial.

In addition to the four models Kent (2000) discusses, the results provide support for the socio-cognitive fear avoidance model (Newell, 2000; 1999). The avoidance and concealment detailed in the 'Hiding Away' sub-theme provided an indication that avoidant behaviours are adopted but, ultimately, can lead to a restriction in activities and exposure as the feared context is circumnavigated. Consequently, strategies and techniques that may

alleviate it are never acquired, and a level of isolation may be experienced (This Lonely Planet). Similarly, the routine avoidance of certain activities may contribute to the reduced self-confidence and increased self-consciousness discussed within 'Becoming One with Difference.'

The applicability of, and overlap between, each of these models combined with the nature of the accounts provided suggests that the call of Kent (2000) for an integrated or unifying theory of adjustment to visible difference should be heeded. Whilst the Appearance Research Collaboration has offered a working framework of adjustment to disfiguring conditions (reported in Clarke, Thompson, Jenkinson, Rumsey, & Newell, 2014) this is acknowledged by the authors as being a somewhat subjective, provisional, working model, in need of further development and refinement. The current research suggests that such development and refinement should account for the models discussed by Kent (2000) and offered by Newell (2000; 1999). This may be considered a research priority as the lack of a unifying theory remains a substantial and substantive challenge to researchers concerned with the psychosocial aspects of visible difference and may impede the provision of holistic healthcare.

### **Clinical Implications**

The accounts of participants and, particularly, the sub-theme 'This Lonely Planet' suggest that visible difference can entail considerable psychosocial difficulties. In addition, professional support may be inadequate, unavailable, or may fail to fully acknowledge these concerns. Some of the episodes that participants recounted in relation to this topic had occurred several years before and so it is possible that patients' experiences may be different today, although ensuring healthcare professionals are aware of the potential impact of visible difference and are able to respond sensitively should be considered a priority. This is especially pertinent as dedicated psychological support for visible difference may not always be readily available.

Access to this support may fluctuate as a factor of the condition with which the patient presents. For example, psychological support is embedded within the multidisciplinary care that NHS Cleft Lip and Palate services provide to children and young people and may feature within services providing care for Burns and Cancer, but may not be routinely offered to those with other conditions, such as dermatology patients. Furthermore, the extent to which appearance concerns are addressed within these services may vary. Whilst a dedicated service named 'Outlook' has been established in Bristol to provide psychological support to those with visible difference, it remains unique within the UK and elsewhere.

Offering psychological support to all persons with a visible difference may be resource intensive but this study suggests that the healthcare experience may be improved where healthcare professionals are aware of their patients' appearance concerns and are willing to acknowledge these as key influences on their well-being. Participants' desire for peer and expert-patient support coupled with the small number of distressing experiences reported in connection with peer support groups indicates that formal healthcare structures and professionals could perform a role in facilitating, guiding, and supporting this interaction in an economical, cost effective manner.

## **Limitations**

This research provided participants a choice of how to engage with the research. The accounts offer rich insights into the experience of those with visible difference and how these experiences may relate to theory and to the provision of healthcare. The research was, however, conducted primarily with persons recruited through support groups and charities that operate within this field. The experiences and beliefs of the participants concerning their visible difference and the subsequent analysis of their accounts, may therefore not reflect or include those who are less engaged with such organisations.

The participants were predominantly women and so whilst the experiences of men were captured, women's experiences are more strongly represented. All interviews were

conducted by the first author, a male researcher who does not consider himself to have a visible difference. It is possible that these personal characteristics may have influenced the willingness of potential participants to engage with the research, the nature of the accounts provided, and the approach to the analysis of the data.

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## Appendix B1: EFA: Relevant Concepts and Ideas for Inclusion in Draft Scale

Ideas and concepts that should be represented in the draft scale long list of items.

### Source: Qualitative Study

- General importance of appearance within domain of intimate relationships (*Appearance Attracts and Detracts*)
- Importance of appearance to initial impressions / judgements about potential partner (*Looking for Love*)
- Stigma
  - attaches to visible difference and reduce romantic possibilities (*Looking for Love*)
  - attaches to visible difference potentially socially contagious to partner (*Looking for Love*)
- Appearance as a barrier to initiation of relationships (*Looking for Love*)
- Only route into a relationship is via friends first (*Looking for Love*)
- Uncertainty / suspect insincerity about what potential / partners feel or say about importance of appearance (when positive) (*Looking for Love*)
- Discount self as viable romantic partner (*The Discounted Self*)
  - Don't deserve interest / attention (*Deficient Me*)
  - Disbelieve attention / interest (*Deficient Me*)
  - Friends or lover but not both (*Deficient Me*)
  - Attractiveness limited by appearance (*Deficient Me*)
  - Difference to feminine/masculine/sexualised part of body (*Deficient Me*)
- Accept self as a potential partner (need accept self before others can) (*The Discounted Self*)
- Social pressure to be physically attractive (*The Discounted Self*)
  - Ability to compensate for visible difference (*Deficient Me*)
  - Ability to work around visible difference (*Deficient Me*)
- Fear (*The Discounted Self*)
  - Avoid approaching others
  - Reject approaches of others
  - Aversive physical reaction to romantic interest
  - Outcomes better than expected

- Comments of others (*The Discounted Self*)
  - Partner / ex-partner
  - Weapon / weakness
- Settle for another person as not good enough / lack choice (*The Discounted Self*)
- Give up on having relationship (*The Discounted Self*)
- Project own feelings onto others (*Deficient Me*)
- Lucky to have accepting partner (*Deficient Me*)
- Surprised to have accepting partner (*Deficient Me*)
- Nervous about disclosing visible difference to new partner (*The Disclosure Dilemma*)
  - Timing
  - Feeling of lying / dishonesty
  - Reaction of other
  - Planning
  - Cooling of interest of the other
- Uncertainty over dating profile pictures (*The Disclosure Dilemma*)
- Potential for it to be an intimate exchange in itself (*The Disclosure Dilemma*)
- Aware of difference before physical intimacy (*Invading Physical Intimacy*)
- Aware of difference during physical intimacy (*Invading Physical Intimacy*)
- Reduced sexual desire (*Corporeal Disinclination*)
- Avoid sexual activity (*Corporeal Disinclination*)
  - Reject advances of partner
- Avoid particular physical acts (*Corporeal Disinclination*)
- Feel physically unattractive (*Corporeal Disinclination*)
- Prolonged periods of sexual inactivity (*Corporeal Disinclination*)
- Believe partner would not want to engage in sexual activity (*Corporeal Disinclination*)
- Discomfort / unease at being seen by partner (*The Shrouding*)
- Cover up: clothes / bedclothes (*The Shrouding*)
- Desire normality – not cover up once ‘fixed’ (*The Shrouding*)
- Preoccupied or unable to be in the moment during sexual activity (*Stealing the Moment*)
- Alter sexual activity / positions (*Stealing the Moment*)
- Aversive reaction to the thought of contact (*Stealing the Moment*)
- Concern over genetic / heritable nature (*Selfish Genes*)
  - Guilt – impact visible difference may have upon their lives
  - Factor in to decision as to have children

- Exposure and acceptance
- Desire intimate relationship that don't have (*Looks Help Delineate and Define Relationships*)
  - Feel failure for not having
- Hypothetical re if existing relationship ended (*Looks Help Delineate and Define Relationships*)
- Only viable way to relationship is via being friends first (*Enriching and Fortifying Us*)
- Vis diff as something to be overcome together (*Enriching and Fortifying Us*)
- Vis diff to lead to enduring and legitimate relationship (*Enriching and Fortifying Us*)
- Vis diff rules out some possible types of relationship / encounter (i.e. more casual ones) (*Enriching and Fortifying Us*)
- Would not be same person but for vis diff (*Enriching and Fortifying Us*)
  - Indirect impact on relationship via this mechanism
- Response says something about the other person and suitability as a partner (*The Litmus Test*)
- Others responsible and accountable for how respond to difference (*The Litmus Test*)
- Disclosure has the possibility to be a positive experience (*The Litmus Test*)
- Double standards applied between self and partner / potential partner (*The Litmus Test*)
- Requires someone special to accept me (*The Litmus Test*)
- Acceptance of me as attractive trait that may lower other standards when considering the other (*The Litmus Test*)
- Able to discuss vis diff with partner (*Treasured Support*)
- Know how partner feel about me and my appearance (*Treasured Support*)
- Believe what partner says about me and appearance (*Treasured Support*)
- Partner provides safety and comfort making more comfortable in rest of activities / contexts (*Treasured Support*)
- Partner is able to understand impact on thoughts, feelings and emotions (*Treasured Support*)
- Sensitivity to comments of partner (*Treasured Support*)
  - And / or ex partner
- No-one to talk to about vis diff and intimacy (*Treasured Support*)

### **Source: Previous Literature<sup>1</sup>**

- Meeting new people as a challenge (Barke, Harcourt, & Coad, 2014)
- Feel others avoid me (Houston & Bull, 1994)
- Anxiety over perceptions of sexual attractiveness (Batty et al., 2014)
  - Even in absence of explicit rejection (Griffiths et al., 2012; Milligan & Neufeldt, 2001)
- Loss of desirability as sexual partner (Batty et al., 2014)
- Active management of visual info – concealment and exposure (Batty et al., 2014)
- Compensatory strategies (Batty et al., 2014)
- Exclusion of affected area from sexual encounters (Batty et al., 2014)
- Consider self sexual human being (Milligan & Neufeldt, 2001; Worthington, 1988)
- Considered by others as a sexual human being (Worthington/Bernstein, 1988) (Milligan & Neufeldt, 2001; Worthington, 1988)
- Believe intimate relationships impossible (Clarke, 1999)
- Consideration, support and acceptance from significant partner (Egan et al., 2011)
- Feel stigmatised by family / significant others (Furr, 2014)
- Sexual worth lost (Furr, 2014)
- Feelings of being unattractive (Griffiths et al., 2012)
- Physical appearance important to developing romantic relationships (Griffiths et al., 2012)
- Hopelessness at prospect of developing romantic relationship (Griffiths et al., 2012)
- Fear negative evaluation (Griffiths et al., 2012)
- Fear intimacy / being rejected during intimacy (Griffiths et al., 2012)
- Concealment, revelation, guilt, confusion (Griffiths et al., 2012)
- Difficulty talking to other (desired) sex (Griffiths et al., 2012)
- Others don't notice / unattractive as normal / part of me / valuing other attributes / in control = all protective (possible reverse score) (Griffiths et al., 2012)
- What is beautiful is good. Subscribe? (Halioua et al., 2011)
- Own perception of noticeability (Rumsey, Clarke, & White, 2003)
- Unable to relax and enjoy sex (Bukovic et al., 2005)
- Incomplete / damaged good / identity (masculinity) (Carpentier et al., 2011)
- Hesitation / postponement of sex (Carpentier et al., 2011)

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<sup>1</sup>please note: this includes reference to a small amount of literature that has been consulted but not included in the final version of the thesis. The additional references included in Appendices B1 and B2 and that are not included within the thesis reference list appear at the end of Appendix B3

- Initiate and maintain conversations, eye contact, body language, tell about history (all things they say interventions could address = potentially ask about ability to do so) (Carpentier et al., 2011)
- Inhibit contact with other (desired) sex (Chrissopoulos and Cleaver, 1996)
- Physical contact as threatening and unwelcome (Chrissopoulos and Cleaver, 1996)
- Isolation / loneliness / lack of support (Chrissopoulos and Cleaver, 1996)
- Avoid intimate relations (Fox, et al., 2007)
- Spouses / partners ashamed (Gamba, et al., 1992)
- Lowered perception of sexual attractiveness (Gilbert, Ussher, & Perz, 2013)
- Area affected – genitalia / exposed areas (Goncalves et al., 2014)
- Satisfaction with sex life (Hannah et al., 1992)
- Concern never form an intimate relationship (Holmberg et al., 2001)
- Work hard to please as convinced not good enough (Kent, 2000)
- Interfere sexual desire and spontaneity (Ghizzani, Pirtou, Bellezza, & Velicogna, 1995)
- Feel at ease with partners (Loaring et al., 2015)
- Cover up / fear sex / worried of husband perception of body / incompleteness / husbands reassure but disbelieve / think about what partner seeing / fear intimacy / fear rejection / not see self as sexual being (Loaring et al., 2015)
- Don't discuss as fear partner finds unattractive (Loaring et al., 2015)
- Fear rejection / remove clothes = on show / avoidance / shame (Magin et al., 2010)
- Disclosure / fear rejection / screening / caution about who involved with (Mathias and Harcourt, 2014)
- Openness and communication = key within previous relationship (before onset) (O'Brien et al., 2012)
- Embarrassment at showing body ./ meeting strangers (Porter et al., 1990)
- Friends as best route to relationship (Shuttleworth, 2000)
- Impact masculinity (Shuttleworth, 2000)
- Disconnect with existing partner / grown apart (Taylor, 2014)
- Appearance as increasing issue as away from treatment (Tindle et al., 2009)
- Need feel comfortable with own ID / less susceptible to judgements of others (Tindle et al., 2009)
- Disclosure issues (Mathias & Harcourt, 2014; Tindle et al., 2009)
- Projection – assume that as appalled by vis difference, everyone else will be too (Tindle et al., 2009)
- Conflict with partner (Wahl et al., 2002)

- Burden on partner (Wahl et al., 2002)
- Experience of body as disgusting and unattractive / transfer of feelings to partner (Wahl et al, 2002)
- Not having partner as inherent in condition (Williams, Gannon, & Soon, 2011)
- Impact communication / interaction with others (Clarke, 1999; Williamson & Wallace, 2012)
- Casual / non sexual physical contact (plus sex / sexual physical contact) (A. Clarke suggestion from clinical experience)
- ARC Scale covers feelings of attractiveness, socialising, kissing, intimate touch, sex enjoyment, lights off, someone new seeing naked, concealment during sex, hugging / being physically close, negative effect on sex life, comfort in intimate situations (ARC reported in Clarke et al., 2013)

## Appendix B2: EFA: Draft Items

### From Qualitative Work

1. *A potential new partner would judge me negatively because of my appearance. (looking for love)*
2. *My appearance means that fewer people would be interested in me as a romantic partner [than would otherwise be the case] (looking for love)*
3. *A partner of mine would feel embarrassed to be seen with me in public. (looking for love / the disclosure dilemma / treasured support)*
4. *The way I look means that I would need to be friends with someone before they would consider me as a romantic partner. (looking for love)*
5. *Because of the way I look I would not consider a casual or fleeting sexual relationship that I may otherwise desire (looking for love)*
6. *My appearance negatively impacts my sense of masculinity/femininity (looking for love / invading physical intimacy)*
7. *Meeting a potential partner for the first time is more daunting because of my appearance (looking for love / the disclosure dilemma)*
8. *I am satisfied with my romantic life (looking for love) (will be covered by other measures)*
9. *How I look has reduced my satisfaction with my intimate and romantic life (looking for love / the discounted self)*
10. *I would find it difficult to believe a partner or potential partner if they told me that my appearance was not important to them (the discounted self)*
11. *There is more social pressure on me to be physically attractive than there is on most other people / There is a lot of social pressure on me to be physically attractive (looking for love / the discounted self)*
12. *I have concerns about using dating websites because of how I look (looking to love / the disclosure dilemma)*
13. *[Due to my appearance] I don't deserve the romantic interest and attention of others (the discounted self)*
14. *[My appearance means that] I find it difficult to believe that the romantic interest and attention of others is genuine (the discounted self)*
15. *Other people would consider me as a friend or as a casual sexual partner but not as a committed romantic partner (the discounted self)*
16. *My level of attractiveness is limited by the way I look (the discounted self)*

17. *[My appearance means that] I am not a worthy romantic partner **(the discounted self)***
18. *[Because of the way I look] It is important that I have other attractive qualities [that are not related to my appearance] **(the discounted self)***
19. *The way I look means that I would avoid approaching someone that I was interested in romantically **(the discounted self)***
20. *[When single] I would reject the romantic approach of another person because of how I feel about how I look **(the discounted self)***
21. *I need to love and accept my own appearance more before I can enjoy a rewarding romantic relationship **(the discounted self)***
22. *The attention of someone who is interested in me romantically would lead to a nervous or anxious physical reaction on my part **(the discounted self)***
23. *The attention of someone who is interested in me romantically would make me feel nervous or anxious **(the discounted self)***
24. *My appearance is something which a partner or ex-partner could use [to hurt me with / against me] if they wished **(the discounted self)***
25. *Because of the way I look, my expectations of a partner are lower [than they would otherwise be] **(the discounted self)***
26. *My appearance means that I do not have a very wide choice of romantic partners **(the discounted self)***
27. *I will never have a rewarding and satisfying intimate relationship **(the discounted self)***
28. *I would be/am very lucky to have a romantic partner accept me for who I am **(the discounted self)***
29. *I would be/am surprised to find a romantic partner who accepts me for who I am **(the discounted self)***
30. *I would [be nervous about] someone new seeing me naked **(the disclosure dilemma / invading physical intimacy)***
31. *I would be nervous about showing my body to a new romantic partner **(the disclosure dilemma / invading physical intimacy)***
32. *If I did not discuss my appearance with a new romantic partner then I would feel I was being dishonest towards them **(the disclosure dilemma)***
33. *I would not know when to tell a new romantic partner about my appearance **(the disclosure dilemma)***
34. *I would not know how to tell a new romantic partner about my appearance **(the disclosure dilemma)***

35. I would be nervous telling a new romantic partner about my appearance **(the disclosure dilemma)**
36. A new romantic partner would be put off me if they knew about my appearance **(the disclosure dilemma))**
37. I would find it difficult to choose a picture of myself to present to potential romantic partners **(the disclosure dilemma)**
38. I would feel obliged to tell a new romantic partner about my appearance at the first opportunity **(the disclosure dilemma)**
39. I would be aware of my appearance immediately prior to sex **(invading physical intimacy)**
40. I would be aware of my appearance during sex **(invading physical intimacy)**
41. I have a reduced desire for sex because of my appearance **(invading physical intimacy)**
42. I avoid sex or certain sexual activity because of my appearance **(invading physical intimacy)**
43. I would reject sexual advances of a romantic partner because of the way I look **(invading physical intimacy)**
44. I would reject the sexual advances of a potential new romantic partner because of the way I look **(invading physical intimacy)**
45. My appearance makes me feel physically unattractive **(invading physical intimacy)**
46. I have experienced prolonged spells of sexual inactivity because of the way I look **(invading physical intimacy)**
47. I do not believe that a romantic partner would feel sexual desire for me **(invading physical intimacy)**
48. I would feel discomfort at being seen naked by a romantic partner **(invading physical intimacy)**
49. I would use clothes, bedclothes or lighting to cover or hide my body or parts of it during sex **(invading physical intimacy)**
50. During sex I would try to hide my body or parts of it from my partner **(invading physical intimacy)**
51. I would be unable to fully enjoy sex because I would be thinking about my appearance **(invading physical intimacy)**
52. My appearance would make me alter my sexual behaviour or activity **(invading physical intimacy)**
53. I feel uncomfortable at the thought of physical contact with another person **(invading physical intimacy)**

54. *I would feel guilt at the thought of passing on my appearance to any children I had*  
**(selfish genes)**
55. *My appearance is one factor that would be relevant to any decision I made about whether to have children or not* **(selfish genes)**
56. *I would not have children because of how I look* **(selfish genes)**
57. *A partner or potential partner's reaction to my appearance would tell me something about how attractive I am* **(the litmus test)**
58. *A partner or potential partner's reaction to my appearance would tell me something about their qualities as a person* **(the litmus test)**
59. *Speaking to a new or potential partner about my appearance would bring us closer together* **(the litmus test)**
60. *Showing a new or potential partner my body would bring us closer together* **(the litmus test)**
61. *It would take someone special to accept me as a romantic partner* **(the litmus test)**
62. *I would be more attracted to somebody because they expressed a romantic interest in me* **(the litmus test)**
63. *I would feel able to discuss my appearance with my/a romantic partner* **(the litmus test)**
64. *My appearance has contributed to rewarding and enduring romantic relationships*  
**(enriching and fortifying us)**
65. *The way I look has led to an improvement in the quality of my romantic relationships*  
**(enriching and fortifying us)**
66. *I am confident that I know how my romantic partner(s) feel (or felt) about my appearance* **(treasured support)**
67. *I would believe a romantic partner if they told me that they find me physically attractive* **(treasured support)**
68. *My romantic partner provides me with support and comfort* **(treasured support)**
69. *My romantic partner understands how I feel about my appearance* **(treasured support)**
70. *Speaking about my appearance with someone I cared about would be a rewarding and enriching exchange* **(treasured support)**

**From ARC Previous Scale (reported in Clarke et al., 2014 and via personal correspondence)**

These four discriminated student / VD sample (normally distributed in student sample) and were recommended to form the basis of future iterations. Scored as 5 point Likert (strongly agree to strongly disagree) plus a not applicable option.

71. *I prefer sex with the light off because it means that my body cannot be seen*  
**(concealment / safety behaviour / sex)**
72. *I feel that I could face the prospect of someone new seeing what I look like naked.*  
**(disclosure / initial apprehension / sex)**
73. *During sex, I use/would use concealing clothing and/or choose positions to hide aspects of my appearance.* **(concealment / sex)**
74. *I feel comfortable with my appearance in intimate situations.* **(self-confidence / sex)**

#### **From Literature<sup>2</sup>**

75. *My appearance makes meeting new people challenging* (Barke et al., 2014)
76. *Others avoid me because of my appearance* (Houston & Bull, 1994)
77. *Other people do not perceive me as being sexually attractive* (Batty et al., 2014)
78. *Other people do not desire me sexually* (Batty et al., 2014)
79. *I would be careful to control what my partner sees of my body* (Batty et al., 2014)
80. *I would be careful to control what a new partner sees of my body* (Batty et al., 2014)
81. *I would conceal my body or parts of it during sex* (Batty et al., 2014)
82. *I consider myself to be a sexual being* (Milligan & Neufeldt, 2001; Worthington, 1988)
83. *Other consider me to be a sexual being* (Milligan & Neufeldt, 2001; Worthington, 1988)
84. *I do not believe it is possible for me to have a rewarding, satisfying, enriching intimate relationship* (Clarke, 1999)
85. *I receive consideration, support and acceptance from an intimate partner* (Egan et al., 2011)
86. *I feel stigmatised by members of my family or a significant other* (Furr, 2014)
87. *I do not have worth as a sexual being* (Furr, 2014)
88. *I feel unattractive* (Griffiths et al., 2012)
89. *My physical appearance is important in developing romantic relationships* (Griffiths et al., 2012)
90. *My physical appearance is important in maintaining romantic relationships* (Griffiths et al., 2012)
91. *I feel that there is no hope of me developing a romantic relationship* (Griffiths et al., 2012)

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<sup>2</sup> please note: this includes reference to a small amount of literature that has been consulted but not included in the final version of the thesis. The additional references included in Appendices B1 and B2 and that are not included within the thesis reference list appear at the end of Appendix B2

92. *I fear being negatively judged by a partner or potential partners on the basis of my appearance* (Griffiths et al., 2012)
93. *I fear being rejected by a romantic partner because of my appearance* (Griffiths et al., 2012)
94. *I fear being rejected by a romantic partner when they see my body* (Griffiths et al., 2012)
95. *My appearance means that , I find it difficult to talk to people that I am attracted to* (Griffiths et al., 2012)
96. *A partner or potential partner would not notice my appearance* (Griffiths et al., 2012)
97. *I am unable to relax and enjoy sex* (Bukovic et al., 2005)
98. *My appearance makes me a less valuable romantic partner* (Carpentier et al., 2011)
99. *I would postpone having sex with a new partner because of how I look* (Carpentier et al., 2011)
100. *I would hesitate before having sex because of my appearance* (Carpentier et al., 2012)
101. *Due to my appearance I have limited contact with people who I am interested in romantically* (Chrissopoulos and Cleaver, 1996)
102. *I find physical contact with a partner threatening* (Chrissopoulos and Cleaver, 1996)
103. *I find physical contact with a partner unwelcome* (Chrissopoulos and Cleaver, 1996)
104. *I feel isolated from other people* (Chrissopoulos and Cleaver, 1996)
105. *I am lonely* (Chrissopoulos and Cleaver, 1996)
106. *I do not feel supported by anyone* (Chrissopoulos and Cleaver, 1996)
107. *I avoid intimate relationships because of how I look* (Fox, et al., 2007)
108. *A romantic partner of mine would feel ashamed of me* (Gamba, et al., 1992)
109. *I am not sexually attractive* (Gilbert et al., 2013)
110. *I am satisfied with my sex life* (Hannah et al., 1992)
111. *I am worried that I will never form a romantic relationship* (Holmberg et al., 2001)
112. *I feel that I need to put extra effort into my relationships because of how I look* (Kent, 2000)
113. *My appearance means I feel less sexual desire* (Ghizzani et al., 1995)
114. *My appearance makes it difficult to be sexually spontaneous* (Ghizzani et al., 1995)
115. *I would feel relaxed and at ease with a partner* (Loaring et al., 2015)
116. *During sex I think about what me partner can see* (Loaring et al., 2015)

117. *I am worried about what my partner or a potential partner thinks about my appearance* (Loaring et al., 2015)
118. *I would not believe a significant other if they tried to reassure me about my appearance* (Loaring et al., 2015)
119. *I would not discuss my appearance with a partner* (Loaring et al., 2015)
120. *Discussing my appearance with a partner would make me less attractive to them* (Loaring et al., 2015)
121. *I would feel ashamed to take my clothes off in front of someone* (Magin et al., 2010)
122. *My appearance makes me more careful about who I become romantically involved with* (Magin et al., 2010)
123. *I am able to communicate effectively with romantic partners* (O'Brien et al., 2012)
124. *I feel embarrassed to show someone my body* (Porter et al., 1990)
125. *I feel embarrassment at meeting strangers* (Porter et al., 1990)
126. *My appearance would create some emotional distance between me and a partner* (Taylor, 2014)
127. *My appearance has led to me and a partner growing apart* (Taylor, 2014)
128. *I compare my appearance to more attractive people* (Taylor, 2014)
129. *Because of how I look I assume that a partner or potential partner would not be attracted to me* (Tindle et al., 2009)
130. *My appearance leads to conflict in my romantic relationships* (Wahl et al., 2002)
131. *My appearance is a burden on a romantic partner* (Wahl et al., 2002)
132. *I feel my appearance is unattractive so a partner would also feel this* (Wahl et al., 2002)
133. *It is normal for people who look like me to not have a partner* (Williams et al., 2011)
134. *Non-sexual contact with a partner would make me feel uncomfortable* (A. Clarke)
135. *Avoid undressing in front of partner* (Carr, DAS 59 & 24)
136. *Adverse effect on sex life* (Carr et al., 2000; 2005)
137. *Adverse effect on marriage* (Carr et al., 2000; 2005)
138. *I would feel comfortable telling a romantic partner my innermost thoughts and feelings about my appearance* (Descutner & Thelen, 1991)
139. *I would share thoughts about my appearance with a romantic partner even if I did not share these with anyone else* (Descutner & Thelen, 1991)
140. *I have shied away from opportunities to get close to someone because of my appearance* (Descutner & Thelen, 1991)

141. *I have held my feelings about how I look back from a romantic partner* (Descutner & Thelen, 1991)
142. *Confide / keep personal info to self* (Miller & Lefcourt, 1982) (covered by others)
143. *How a romantic partner feels about my appearance is important to me*
144. *I would [be aware of / feel uncomfortable about/ feel bad about feel physically unattractive because of] my appearance during sex[ual activity]* (McDonagh et al, 2009; Wiederman, 2000)
145. *The first time I have sex with , I would worry that my partner would find me physically unattractive* (McDonagh et al, 2009)
146. *The worst thing about having sex is being naked in front of another person* (McDonagh et al, 2009; Wiederman, 2000)

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## Appendix B3: 73 Grouped Items

Romantic relations and physical intimacy related appearance anxiety and distress:  
concepts

- **Diminished value as partner**
  - Self evaluated
  - Less choice of partner
- **Negatively evaluated by others**
- **Disclosure to new partner**
- **Initiation caution/apprehension/viability**
- **Established relationship**
  - Openness
  - Support
- **Sex and physical intimacy**
  - Safety behaviours
  - Anxiety / discomfort
  - Appearance consciousness
  - Avoidance / inactivity

### Diminished value

*self*

1. (56) *I feel physically attractive (x)*
2. (38) *The romantic or sexual interest of others in me is genuine (x)*
3. (9) *A partner of mine would be embarrassed or ashamed to be seen with me in public*
4. (31) *I need to put extra effort into my relationships because of how I look*
5. (26) *I deserve the romantic interest and attention of others (x)*
6. (55) *It is important that I have attractive qualities that are not to do with my looks*
7. (5) *I will never have a rewarding romantic relationship*

*Partner choice reduced*

8. (36) *It is normal for people like me to be single*
9. (42) *It would take someone special to accept me as a partner*
10. (17) *I would be lucky to find a partner who accepts me for who I am*

11. (13) *I have a wide choice of partners (x)*
12. (58) *I would be attracted to somebody because they expressed romantic interest in me*

### **Negative Evaluation**

13. (48) *Other people are physically attracted to me (x)*
14. (35) *Other people are repelled by my appearance*
15. (70) *A new partner would be put off by my appearance*
16. (43) *A partner would feel little sexual desire for me*
17. (6) *Other people find me sexually attractive (x)*
18. (61) *A potential new partner would judge my appearance negatively*
19. (1) *My attractiveness to others is limited by my appearance*
20. (4) *I would fear being rejected by a partner*
21. (27) *I would fear being rejected by a potential partner*

### **Apprehension / caution in relationship initiation**

22. (3) *I would reject the romantic approach of another person*
23. (72) *Receiving the romantic attention of another person would make me feel anxious*
24. (11) *I find it difficult to talk to people that I am attracted to*
25. (63) *I would approach someone that I was attracted to (x)*
26. (29) *My appearance is an extra barrier to me developing romantic relationships*
27. (34) *I would avoid using dating websites*
28. (50) *I would need to be friends with someone before becoming partners*
29. (19) *I am careful about who I become romantically involved with*

### **Disclosure**

30. (2) *Showing a new partner my body would bring us closer together (x)*
31. (10) *I would know when to tell a new partner about my appearance (x)*
32. (65) *I would know how to speak to a new partner about my appearance (x)*
33. (62) *I would be worried about telling a potential or new partner about my appearance*
34. (28) *I would find it difficult to choose a picture of myself to present to potential partners*
35. (49) *I would be worried about a potential or new partner seeing me naked*
36. (37) *It would be deceitful not tell a new partner about my appearance very early in the relationship*

## **Partner Relationship**

### *Openness*

- 37. (57) *Speaking about how I look with a partner would be a positive experience (x)*
- 38. (12) *I would feel able to openly discuss my appearance with a partner (x)*
- 39. (30) *I would withhold my feelings about how I look from a romantic partner*
- 40. (20) *Discussing my appearance with a partner would make me less attractive to them*
- 41. (41) *I would feel comfortable telling a partner my innermost thoughts and feelings about how I look (x)*
- 42. (18) *Speaking to a new partner about my appearance would bring us closer together (x)*

### *Support*

- 43. (71) *My partner would be able to provide me with support and comfort if I felt unhappy about how I look (x)*
- 44. (46) *My partner could understand how I feel about my appearance (x)*
- 45. (67) *I am satisfied with my intimate and romantic life (x)*
- 46. (51) *I grow apart from my partners or experience conflict in my relationships because of my appearance*
- 47. (21) *A partner or ex-partner could use the way I look against me or to hurt me*

## **Sex and Physical Intimacy**

### *Safety*

- 48. (68) *During sexual activity, I would use clothing, lighting or choose certain positions to hide aspects of my appearance*
- 49. (53) *I would alter my sexual behaviour because of how I look*
- 50. (8) *I engage in less sexual activity than I would otherwise because of my appearance*
- 51. (24) *I would avoid undressing in front of a partner*
- 52. (39) *I prefer sexual activity with the light off so that I cannot be seen*

### *Sexual Inactivity / Avoidance*

- 53. (66) *I would postpone engaging in sexual activity with a new partner because of how I look*
- 54. (60) *I would avoid sexual activity with a new partner because of how I look*
- 55. (32) *I avoid certain sexual activity because of how I look*

- 56. (54) *I would avoid sexual activity with an established partner because of my appearance*
- 57. (16) *I have experienced prolonged spells of limited or no sexual activity [extreme response 6]*
- 58. (47) *I would be comfortable engaging in a casual or fleeting sexual relationship (x)*

#### *Anxiety / discomfort*

- 59. (59) *I feel anxious immediately prior to sexual activity*
- 60. (45) *I feel anxious during sexual activity*
- 61. (22) *I have a reduced desire for sexual activity because of my appearance*
- 62. (64) *The prospect of sexual contact makes me feel uncomfortable*
- 63. (23) *I feel comfortable when a partner touches my body in a sexual manner (x)*
- 64. (44) *I welcome sexual contact with a partner (x)*
- 65. (73) *The first time I engage in sexual activity with a new partner, I would worry that my partner would find me unattractive*
- 66. (25) *Non-sexual physical contact with a romantic partner would make me feel uncomfortable*
- 67. (15) *I would be comfortable hugging and holding my partner's hand (x)*
- 68. (74) *I would feel comfortable kissing my partner (x)*

#### *Appearance Consciousness*

- 69. (69) *I feel comfortable with my appearance in sexual situations (x)*
- 70. (33) *I am able to relax and fully enjoy sexual activity (x)*
- 71. (40 / 52) *I feel discomfort at being seen naked by a partner*
- 72. (7) *I would feel comfortable being naked in front of my partner (x)*
- 73. (14) *During sexual activity I think about what my partner can see*

*x = will be reverse scored*

## Appendix B4: EFA Complete Questionnaire

### Demographic Information

1. What is your gender?

Female	Male	Unspecified
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. What is your age (in years):

3. What is your ethnic group?

White	Mixed / Multiple Ethnic Groups	Asian / Asian British	Black / African / Caribbean / Black British	Any other ethnic group (please describe)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<div>-----</div> <div>----</div>

4. What is your religion?

No religion	Christian (all denominations)	Buddhist	Hindu	Jewish	Muslim	Sikh	Any other religion (please describe)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<div>-----</div>

5. Which of the following options best describes how you think of yourself?

Heterosexual or Straight	Gay or Lesbian	Bisexual	Other (please describe)	Prefer not to say
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<div>-----</div>	<input type="checkbox"/>

6. Which one of the following options best describes your current relationship status?

Single	Separated, divorced or widowed (no current partner)	In a relationship but living separately	In a relationship and living together	Married or in a civil partnership
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7. Do you consider yourself to have a visible difference (by this we mean an altered appearance or disfiguring condition that in some way makes you feel you look different to others)?

Yes	No
<input type="checkbox"/>	<input type="checkbox"/>

***Please only answer questions 8-14 if you answered Yes (you do have a visible difference) to question 7***

***Please proceed to question 15 if you answered No (you do not have a visible difference) to question 7***

- 8. Is your difference normally visible to other people in everyday life? (if you routinely cover or disguise it and feel that people do not normally notice, please answer 'no')**

Yes	No
<input type="checkbox"/>	<input type="checkbox"/>

- 9. How did your visible difference arise?**

Congenital / inherited / genetic	<input type="checkbox"/>
Traumatic Injury	<input type="checkbox"/>
Disease Process	<input type="checkbox"/>
Treatment / Surgery	<input type="checkbox"/>
Other	<input type="checkbox"/>
(please describe)	-----

- 10. If your visible difference was acquired after birth, for how many years have you had it?**

-----

- 11. Which description(s) best describe the nature of your visible difference?**

Alopecia / hair loss	<input type="checkbox"/>
Birthmark	<input type="checkbox"/>
Burn Injury	<input type="checkbox"/>
Craniofacial Condition	<input type="checkbox"/>
Dermatological or Skin condition	<input type="checkbox"/>
Limb Loss or Amputation	<input type="checkbox"/>
Lymphoedema	<input type="checkbox"/>
Scarring	<input type="checkbox"/>
Skeletal condition	<input type="checkbox"/>
Cancer related	<input type="checkbox"/>
(please describe)	-----
Other	<input type="checkbox"/>
(please describe)	-----
Paralysis or muscular weakness	<input type="checkbox"/>

If you would like to provide a little more detail, please do so -----

**12. Which area(s) of your body are affected by your visible difference?**

Legs / Feet	<input type="checkbox"/>
Genitals	<input type="checkbox"/>
Buttocks	<input type="checkbox"/>
Stomach	<input type="checkbox"/>
Chest	<input type="checkbox"/>
Back	<input type="checkbox"/>
Arms / Hands	<input type="checkbox"/>
Shoulders / Neck	<input type="checkbox"/>
Head	<input type="checkbox"/>
Face	<input type="checkbox"/>
Other (please describe)	-----

**13. Are you currently receiving treatment from any healthcare professional in connection with your visible difference?**

Yes	No
<input type="checkbox"/>	<input type="checkbox"/>

**14. How different from normal do you judge the area(s) of your body affected by your visible difference to be?**

Not at all Different			Moderately			Extremely Different
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**15. Overall, how different from normal do you judge your appearance to be?**

Not at all Different			Moderately			Extremely Different
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please read the following statements and consider how strongly you agree or disagree with each of them.

If the question appears to not apply to you because of your current circumstances, for example, if it's about a new relationship but you are currently in a relationship or it mentions a partner but you are currently single, please imagine how you would feel if it was applicable and then choose the option that corresponds to how you would feel. If it is not applicable to you for some other reason, please choose the 'not applicable' option. Please don't spend too long on any one question

	<i>Not Applicable</i>	<i>Strongly Disagree</i>	<i>Moderately Disagree</i>	<i>Slightly Disagree</i>	<i>Slightly Agree</i>	<i>Moderately Agree</i>	<i>Strongly Agree</i>
1. My attractiveness to others is limited by my appearance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Showing a new partner my body would bring us closer together	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I would reject the romantic approach of another person	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I would fear being rejected by a partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I will never have a rewarding romantic relationship	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Other people find me sexually attractive	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I would feel comfortable being naked in front of my partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. I engage in less sexual activity than I would otherwise because of my appearance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<i>Not Applicable</i>	<i>Strongly Disagree</i>	<i>Moderately Disagree</i>	<i>Slightly Disagree</i>	<i>Slightly Agree</i>	<i>Moderately Agree</i>	<i>Strongly Agree</i>
9. A partner of mine would be embarrassed or ashamed to be seen with me in public	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. I would know when to tell a new partner about my appearance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. I find it difficult to talk to people that I am attracted to	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. I would feel able to openly discuss my appearance with a partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. I have a wide choice of partners	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. During sexual activity I think about what my partner can see	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. I would be comfortable hugging and holding my partner's hand	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. I have experienced prolonged spells of limited or no sexual activity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<i>Not Applicable</i>	<i>Strongly Disagree</i>	<i>Moderately Disagree</i>	<i>Slightly Disagree</i>	<i>Slightly Agree</i>	<i>Moderately Agree</i>	<i>Strongly Agree</i>
17. I would be lucky to find a partner who accepts me for who I am	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Speaking to a new partner about my	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

appearance would bring us closer together							
19. I am careful about who I become romantically involved with	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. Discussing my appearance with a partner would make me less attractive to them	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. A partner or ex-partner could use the way I look against me or to hurt me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. I have a reduced desire for sexual activity because of my appearance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. I feel comfortable when a partner touches my body in a sexual manner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. I would avoid undressing in front of a partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. Non-sexual physical contact with a romantic partner would make me feel uncomfortable	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. I deserve the romantic interest and attention of others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<i>Not Applicable</i>	<i>Strongly Disagree</i>	<i>Moderately Disagree</i>	<i>Slightly Disagree</i>	<i>Slightly Agree</i>	<i>Moderately Agree</i>	<i>Strongly Agree</i>
27. I would fear being rejected by a potential partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. I would find it difficult to choose a picture of myself to present to potential partners	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. My appearance is an extra barrier to me developing romantic relationships	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. I would withhold my feelings about how I look from a partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. I need to put extra effort into my relationships because of how I look	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. I avoid certain sexual activity because of how I look	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. I am able to relax and fully enjoy sexual activity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. I would avoid using dating websites	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. Other people are repelled by my appearance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36. It is normal for people like me to be single	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	<i>Not Applicable</i>	<i>Strongly Disagree</i>	<i>Moderately Disagree</i>	<i>Slightly Disagree</i>	<i>Slightly Agree</i>	<i>Moderately Agree</i>	<i>Strongly Agree</i>
37. It would be deceitful not tell a new partner about my appearance very early in the relationship	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. The romantic or sexual interest of others in me is genuine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39. I prefer sexual activity with the light off so that I cannot be seen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40. I feel discomfort at being seen naked by a partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
41. I would feel comfortable telling a partner my innermost thoughts and feelings about how I look	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
42. It would take someone special to accept me as a partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
43. A partner would feel little sexual desire for me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
44. I welcome sexual contact with a partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
45. I feel anxious during sexual activity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
46. My partner could understand how I feel about my appearance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
47. I would be comfortable engaging in a casual or fleeting sexual relationship	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
48. Other people are physically attracted to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<i>Not Applicable</i>	<i>Strongly Disagree</i>	<i>Moderately Disagree</i>	<i>Slightly Disagree</i>	<i>Slightly Agree</i>	<i>Moderately Agree</i>	<i>Strongly Agree</i>
49. I would be worried about a potential or new partner seeing me naked	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
50. I would need to be friends with someone before becoming partners	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
51. I grow apart from my partners or experience conflict in my relationships because of my appearance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
52. I feel discomfort at being seen naked by a partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
53. I would alter my sexual behaviour because of how I look	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

54. I would avoid sexual activity with an established partner because of my appearance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
55. It is important that I have attractive qualities that are not to do with my looks	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
56. I feel physically attractive	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
57. Speaking about how I look with a partner would be a positive experience	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
58. I would be attracted to somebody because they expressed romantic interest in me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<i>Not Applicable</i>	<i>Strongly Disagree</i>	<i>Moderately Disagree</i>	<i>Slightly Disagree</i>	<i>Slightly Agree</i>	<i>Moderately Agree</i>	<i>Strongly Agree</i>
59. I feel anxious immediately prior to sexual activity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
60. I would avoid sexual activity with a new partner because of how I look	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
61. A potential new partner would judge my appearance negatively	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
62. I would be worried about telling a potential or new partner about my appearance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
63. I would approach someone that I was attracted to	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
64. The prospect of sexual contact makes me feel uncomfortable	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
65. I would know how to speak to a new partner about my appearance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
66. I would postpone engaging in sexual activity with a new partner because of how I look	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<i>Not Applicable</i>	<i>Strongly Disagree</i>	<i>Moderately Disagree</i>	<i>Slightly Disagree</i>	<i>Slightly Agree</i>	<i>Moderately Agree</i>	<i>Strongly Agree</i>
67. I am satisfied with my intimate and romantic life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
68. During sexual activity, I would use clothing, lighting or choose certain positions to hide aspects of my appearance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

69. I feel comfortable with my appearance in sexual situations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
70. A new partner would be put off me by my appearance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
71. My partner would be able to provide me with support and comfort if I felt unhappy about how I look	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
72. Receiving the romantic attention of another person would make me feel anxious	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
73. The first time I engage in sexual activity with a new partner, I would worry that my partner would find me unattractive.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
74. I would feel comfortable kissing my partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Is there anything else that you would like to add in connection with your appearance and your intimate relationships or anything that you feel the previous questions have not addressed? If so, please describe here:

Participants then completed measures of:

- **Appearance Distress: The Derriford Appearance Scale 24 (DAS24):** Carr, Moss, and Harris (2005) which measures distress and difficulties experienced in living with problems of appearance.

*Example items:*

*How distressed do you get when you go to the beach?*

*N/A / Not at all / A little / Moderately / Extremely*

*I avoid undressing in front of my partner:*

*Not at all / Never/almost never / Sometimes / Often / Almost always*

- **Fear of Negative Evaluation: The Fear of Negative Evaluation – Brief (FNE-B):** Leary (1983) which measures apprehension about being evaluated unfavourably by others.

*Example item:*

*I am afraid that people will find fault with me*

*Not at all characteristic of me / Slightly characteristic of me / Moderately characteristic of me / Very characteristic of me / Extremely characteristic of me*

- **Body Self-Consciousness During Physical Intimacy:**

As appropriate depending upon participants' sex (anyone identifying non-binary would not complete either). Both scales measure body image self-consciousness during physical intimacy. Either:

The Women's Body Image Self-Consciousness During Physical Intimacy With a Partner Scale (WBISCDPIWPS) (Wiederman, 2000)

*Example item:*

*If a partner were to put a hand on my buttocks I would think, "My partner can feel my fat."*

*Never / Rarely / Sometimes / Often / Usually / Always*

**or**

The Male Body Image Self-Consciousness During Physical Intimacy Scale (MBISCDPIS) (McDonagh, Morrison, & McGuire, 2009)

*Example item:*

*During sex, I would worry that my partner would think my stomach is not muscular enough*

*Strongly Disagree / Disagree / Don't Know / Agree / Strongly Agree*

- **Fear of Intimacy: The Fear of Intimacy Scale (FIS):** (Descutner & Thelen, 1991) which measures fear of intimacy within, and at the prospect of, close relationships.

*Example items ('0' refers to the person the respondent imagines being in a close relationship with):*

*I would feel at ease telling 0 that I care about him/her*

*Not at all characteristic of me / Slightly characteristic of me / Moderately characteristic of me / Very characteristic of me / Extremely characteristic of me*

*I would be afraid of sharing my private thoughts with 0*

*Not at all characteristic of me / Slightly characteristic of me / Moderately characteristic of me / Very characteristic of me / Extremely characteristic of me*

- **Social Intimacy (presence): The Miller Social Intimacy Scale (MSIS)** (Miller & Lefcourt, 1982). which measures the maximum level of intimacy experienced by an individual at the time of completion.

*Example item (he/she is the person to whom the respondent is closet):*

*How important is it to you that he/she understands your feelings?*

*Not much (1-3) – A little (4-7) – A great deal (8-10) (10 point Likert-style response)*

- **'Hysteria' the Crown Crisp Experiential Index (CCEI-H)** (Crown & Crisp, 1979) which was designed to measure hysteria

*Example item:*

*Do you find that you take advantage of circumstances for your own ends?*

*Never / Sometimes / Often*

These measures were randomised within Qualtrics and are not reproduced in full here (due to commercial/copyright considerations) but are each available in the publications cited.

Thank you for giving your time to participate in this study. We are very grateful to you.

As you are aware, we are examining the impact of visible differences upon intimate romantic relationship and the responses you have provided will help us study this under researched area. Our answers to the questions will help us refine and shorten the measurement scale that we are developing and allow us to look at the other questionnaires that you completed and see how the responses to each of them relate to one another and try to understand whether any particular group of people are more likely to experience difficulties with intimacy in connection with their visible difference.

We hope that you did not find participating in this study upsetting or distressing in any way. If you did or if you have any appearance based concerns and you would like contact details of organisations that may be able to provide some assistance then Changing Faces has a list of other organisations that may be able to assist. This includes condition specific organisations, those that advise on general health and those that focus on mental health issues. This list is available from Changing Faces and can be found on its website.

The Centre for Appearance Research also maintains a list of organisations that may be able to provide support for those with concerns about their appearance and this is available from the Centre for Appearance Research and can be found on its webpages.

If you are unable to locate the information referred to above, would like to know more about this work, have any questions about the study or wish to discuss any aspect of this research with the researcher then please contact Nick Sharratt on email at [nick.sharratt@uwe.ac.uk](mailto:nick.sharratt@uwe.ac.uk) or by phone on 0117 328 1891.

The postal address for the Centre for Appearance Research is:

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

Thank you again for your time and participation in this study.

## Appendix B5: EFA: University Research Ethics Committee: Application for Ethical Review of Research Involving Human Participants



University of the  
West of England

### APPLICATION FOR ETHICAL REVIEW OF RESEARCH INVOLVING HUMAN PARTICIPANTS

This application form should be completed by members of staff and PhD/ Prof Doc students undertaking research which involves human participants. Undergraduate and Masters level students are required to complete this application form where their project has been referred for review by a supervisor to a Faculty Research Ethics Committee (FREC) in accordance with the policy at <http://www1.uwe.ac.uk/research/researchethics>. For research using human tissue, please see separate policy, procedures and guidance linked from <http://www1.uwe.ac.uk/research/researchethics/policyandprocedures.aspx>

Please note that the process takes **up to six weeks** from receipt of a valid application. **The research should not commence until written approval has been received from the University Research Ethics Committee (UREC) or Faculty Research Ethics Committee (FREC).** You should bear this in mind when setting a start date for the project.

#### APPLICANT DETAILS

Name of Applicant*	Nicholas David Sharratt		
Faculty	Health and Applied Sciences	Department	Health and Social Sciences: Centre For Appearance Research
Status: Staff/PG Student/ MSc Student/ Undergraduate	PG Student	Email address	nick.sharratt@uwe.ac.uk
Contact postal address	Room 2L13, Frenchay Campus, UWE		
Name of co-researchers* (where applicable)	Professor Nichola Rumsey (DoS)		

\*This form must include the name of the UWE Project Manager (normally the budget holder and PI)

#### FOR STUDENT APPLICANTS ONLY

Name of Supervisor/Director of Studies	Professor Nichola Rumsey (DoS) Dr Elizabeth Jenkinson (Supervisor)
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	Dr Tim Moss (Supervisor)
Detail of course/degree for which research is being undertaken	PhD
Supervisor's/Director of Studies' email address	Nichola.rumsey@uwe.ac.uk
Supervisor's/ Director of Studies' comments	

**For student applications, supervisors should ensure that all of the following are satisfied before the study begins:**

- The topic merits further research;
- The student has the skills to carry out the research;
- The participant information sheet is appropriate;
- The procedures for recruitment of research participants and obtained informed consent are appropriate.

#### PROJECT DETAILS

Project title	The Impact of Visible Differences on Intimacy and Intimate Relationships		
Is this project externally funded?	No		
If externally funded please give PASS reference			
Proposed start date for the research	February/March 2017	Anticipated project end date	June 2017

**Fieldwork should not begin until ethics approval has been given**

#### DETAILS OF THE PROPOSED WORK

1. Aims, objectives of and background to the research
<i>This should provide the reviewer of the application with sufficient detail to allow them to understand the nature of the project and its rationale, and the ethical context, in terms which are clear to a lay reader. Do not assume that the reader knows you or your area of work. You may provide a copy of your research proposal in addition to completing this section. Please try to keep within 500 words.</i>
<p><b>Summary of aims and objectives</b></p> <p>The aim of this research is to better understand the impact of appearance concerns amongst adults that have disfiguring conditions (or 'visible differences') upon intimacy and intimate relationships and the prevalence of such concerns amongst this population. This will be achieved through the development of a measurement scale designed to assess this impact and it is envisaged that this scale will eventually be available for use by those that</p>

work professionally with those that have a visible difference so that it may be utilised to assess those individuals who may benefit from additional support or onward referral or intervention. It is also hoped that the development and deployment of a measurement scale will facilitate and enable a discussion of the intersection of visible difference and intimacy between those affected individuals and healthcare professionals that work with them.

## **Background**

Visible differences or disfiguring conditions have been defined by Kent and Thompson (2002) as 'potentially noticeable differences in appearance that are not culturally sanctioned' and they highlight the three main causes as being congenital conditions, traumatic events and disease. It is well established that these differences can impact negatively upon an individual's life and are associated with a variety of psychosocial difficulties. These difficulties can include depression, social anxiety, reduced quality of life and social avoidance (Rumsey, Clarke and White, 2003).

In light of these psychosocial challenges, one domain of activity that may be negatively impacted is romantic intimate relationships. It is important to understand any such affect as intimate relationships can constitute a principal component of adult human life and have been described as natural, protective and an essential element of our adaptation, functioning and ability to lead healthy, happy lives (Popovic, 2005). Existing research is limited, however a range of challenges have been identified in adolescents and young adults (Griffiths, Williamson and Rumsey, 2012; Carpentier et al, 2011; Fox, Rumsey and Morris, 2007) and also an adult population (Batty, McGrath and Reavey, 2014; Mathias and Harcourt, 2014; O'Brien et al, 2012; Magin et al, 2010) with social avoidance and fear often explicitly cited in explanation of such difficulties.

The current research programme was initiated with a large qualitative interview study (UWE REC REF No: HAS/15/03/132). This has provided deep and unique insights into the experience of intimacy and intimate relationships amongst those that have a visible difference. That research has been instrumental in developing the draft scale items and the current study will enable the draft items to be validated and the scale reduced in length in order that it be capable of future application.

In addition, the qualitative study highlighted that intimacy and visible difference was rarely discussed between participants and the healthcare professionals with many participants feeling unable to voice their appearance concerns. This mirrored similar suggestions in the literature (Verschuren et al, 2013; Penner, 2009; Sheppard and Ely, 2008; Sampogna et al, 2007) that questions of sexuality can be akin to a taboo, especially when set against disability and appearance altering conditions (Mathias and Harcourt, 2014; Geertzen, Van Es and Dijkstra, 2009) and within the clinical context (Dixon and Dixon, 2006). This confirms the objective of creating a scale that may be used to introduce the subject to a clinical discussion and legitimise intimacy as a topic of concern within that situation.

## **2. Research methodology to be used**

*You should explain how you plan to undertake your research. A copy of the interview schedule/ questionnaire/observation schedule/focus group topic guide should be attached where applicable.*

This research will be conducted by employing quantitative methods and by asking participants (see below) to complete the draft (long form) scale (see appendix) that has been developed from the data generated in the prior qualitative study. It is envisaged that most participants will participate on-line , though other options will be available (discussed in section 4).

The data collected will be imported into SPSS and subjected to exploratory factor analysis, the principal factors extracted and labelled and a revised version of the tool generated, potentially including several sub-factors that, if identified, will need to be appropriately labelled. Some items may need to be rewritten and others discarded. Factor analysis will inform the factor structure and items that will be retained, however, the final goal of generating a tool with practical utility and capable of real world application may also influence these decisions. The outcome of the study will be a version of the scale that will be further validated via further research and confirmatory factor analysis. Depending upon the data, it is, however, possible that both a short and long form version of the scale may be a viable outcome if there is a tension between the factor analysis and the need to produce a short, manageable and ultimately useable scale.

Participants will utilize Qualtrics website where the study will be hosted. This (and any paper versions requested) will include (in this order) the participant information sheet, eligibility criteria, the consent form (including the data protection notice), demographic data collection, the intimacy scale, the related measures (discussed below) and a thank you / debrief page. The demographic data will include details of the participant's visible difference (including type, location, visibility, subjective rating of severity), age, sex, ethnicity, sexual orientation, relationship/marital status

To validate the scale (see below) and to independently examine associations between the scale and existing measures and between these existing measures, participants will also be asked to complete a number of other (already validated) measures. These have been (or will be if the precise measures deployed alters between this application and the study opening) selected for their theoretical associations with the prior qualitative data (which has informed the scale items) and therefore with some constructs that the scale may measure. It should be noted that these measures may be subject to change, for example the longer form of the Derriford Appearance Scale may be used or a shorter version of the Fear of Negative Evaluation Scale. This is currently under review with the supervisory team and no measure will be used without the approval of that team. These measures are currently: (briefly)

- *The Derriford Appearance Scale 24* – measuring appearance concern

Carr, T., Moss, T., & Harris, D. (2005). The DAS24: A short form of the Derriford Appearance Scale DAS59 to measure individual responses to living with problems of appearance. *British journal of health psychology*, 10(2), 285-298.

- *The Fear of Intimacy Scale* – measuring the fear of intimacy (non-physical intimacy)

Descutner, C. J., & Thelen, M. H. (1991). Development and validation of a Fear-of-Intimacy Scale. *Psychological assessment: A journal of consulting and clinical psychology*, 3(2), 218.

- *The Miller Social Intimacy Scale* – measuring current levels of intimacy

Miller, R. S., & Lefcourt, H. M. (1982). The assessment of social intimacy. *Journal of personality Assessment*, 46(5), 514-518.

- *The Male Body Image Self-Consciousness During Physical Intimacy Scale: or*
- *The Women's Body Image Self-Consciousness During Physical Intimacy With a Partner Scale*

both measuring body image concerns during physical intimacy

McDonagh, L. K., Morrison, T. G., & McGuire, B. E. (2009). The naked truth: Development of a scale designed to measure male body image self-consciousness during physical intimacy. *The Journal of Men's Studies*, 16(3), 253-265.

Wiederman, M. W. (2000). Women's body image self-consciousness during physical intimacy with a partner. *Journal of sex research*, 37(1), 60-68.

- *The Fear of Negative Evaluation* – measuring evaluative anxiety. A brief version has been selected in light of its validity and in an attempt to keep the number of items that participants are being asked to complete at a more manageable level

Leary, M. R. (1983). A brief version of the Fear of Negative Evaluation Scale. *Personality and Social Psychology Bulletin*, 9(3), 371-375.

- *The 'Hysteria' sub-test contained within the Crown Crisp Experiential Index* – a measure of hysteria that will be used to demonstrate discriminant validity (was used by Carr et al (2005) for the same purposes)

Crown, S., & Crisp, A. H. (1979). *Manual of the Crown Crisp Experiential Index*. London: Hodder and Stoughton

These measures have therefore been/will be selected to help demonstrate the construct validity of the scale. Whilst the scale may not measure or tap a single, identified, defined construct its items may overlap with several constructs that prior scales have measured (as above) and that may also be associated with one another. It is therefore anticipated that there may be a correlation between these other measures and the scale. To achieve convergent validity, participants will thus therefore complete the measures identified above and with which the scale would theoretically be expected to correlate and their correlation examined (Keszei, Novak and Streiner, 2010). Divergent validity will be

assessed through the Crown Crisp Hysteria Sub-scale, with which the scale would not be expected to correlate.

The content and face validity of the scale (Keszei, Novak and Streiner, 2010) has already been assured by consulting with experts within the field from with CAR and with individual collaborators interested in the project, such as the research active clinical psychologist referred to previously. The scale will also be pilot tested for sense, ambiguity and clarity with members of CAR and any necessary adjustments incorporated before participants are recruited to complete the tool.

### 3. SELECTION OF PARTICIPANTS

*You must indicate if any of the participants in your sample group are in the categories listed. Research involving adult participants who might not have the capacity to consent or who fall under the Mental Capacity Act must be reviewed either by an NHS Research Ethics Committee or the [National Social Care Research Ethics Committee](#).*

*If your proposed research involves contact with children or vulnerable adults, or others of the specified categories below, you may need to hold a valid DBS check. Evidence of a DBS check should take the form of an email from the relevant counter signatory confirming the researcher has a valid DBS check for working with children and/or vulnerable adults. It is the responsibility of the applicant to provide this confirmation.*

*Members of staff requiring DBS checks should contact Human Resources [hr@uwe.ac.uk](mailto:hr@uwe.ac.uk). DBS checks for students are usually organised through the student's faculty, but students in faculties without a DBS counter signatory should contact Leigh Taylor ([Leigh.Taylor@uwe.ac.uk](mailto:Leigh.Taylor@uwe.ac.uk)).*

**Will the participants be from any of the following groups? ( 'x' as appropriate)**

- ☐ Children under 18\*
- ☐ Adults who are unable to consent for themselves
- ☐ Adults who are unconscious, very severely ill or have a terminal illness
- ☐ Adults in emergency situations
- ☒ Adults with mental illness (particularly if detained under Mental Health Legislation)
- ☐ Prisoners
- ☐ Young Offenders
- ☐ Healthy Volunteers (where procedures may be adverse or invasive)
- ☐ Those who could be considered to have a particularly dependent relationship with the investigator, e.g. those in care homes, medical students
- ☐ Other vulnerable groups
- ☐ None of the above

*\* If you are researching with children please provide details of completed relevant safeguarding training.*

**If any of the above applies, please justify their inclusion in this research.**

Participants will include those that self-identify as having a visible difference. Whilst this, in itself, does not deem them vulnerable there is a body of research which indicates that for a proportion of the population eligible population, visible differences may be comorbid with psychological distress and adjustment difficulties. These may include some forms of mental illness such as depression and anxiety. The option of excluding any participant with any co-morbid mental health issues was considered but (as is consistent with the qualitative study underpinning the development of the scale) it was felt that doing so would potentially mean that the full range of experiences may not be captured. It may also be considered unnecessarily stigmatising and even unethical to refuse to extend the research to those that have, for example, diagnosed depression on the basis of the diagnosis per se and without considering whether the condition actually impacts upon the individual's ability to consent or to safely participate in the research. Excluding all those with diagnosed conditions may also have meant that for those with mild forms of anxiety or depression (or other conditions) participation would be contingent upon whether a diagnosis had been sought as many such people may remain undiagnosed.

Despite the decision to include those with controlled or and less impactful mental health conditions and in order to minimise any risk to participants and ensure that consent can be freely given and as described below, potential participants detained under applicable legislation or with diagnosed mental health conditions that are uncontrolled (by medication or intervention) and which have a significant impact upon the activities of daily life will not be eligible to participate in this research. This will rely upon participants self-reported answers to screening questions that shall precede the substantive measures on the Qualtrics.

4. Please explain how you will determine your sample size/recruitment strategy, and identify, approach and recruit your participants. Please explain arrangements made for participants who may not adequately understand verbal explanations or written information in English

*In this section, you should explain the rationale for your sample size and describe how you will identify and approach potential participants and recruit them to your study.*

Participants will be adults of at least 18 years old who are able to communicate in the English language (in written form), who identify as having a visible difference and who are not detained under applicable legislation and do not have a diagnosed mental health condition that is uncontrolled (by medication or intervention) and which has a significant impact upon the activities of daily life.

If recruitment does not proceed in a timely manner (which parameters shall be agreed with the supervisory team) it is possible that the study may be extended to include some participants who do not have a visible difference. Whilst this is not being done initially as the focus of this work is those with a visible difference, it is theoretically sound so long as the underlying factor structure of the two populations does not differ. At present there is no evidence to suggest that there is any such difference. The two populations may (in general) sit at different points on the scale and so the responses may be quantitatively

different (as some existing research has suggested) but this does not necessarily mean that the factor structure will vary. If this eventuality does transpire the similarity of the factor structures can be compared to ensure that this is not problematic. If they do vary then this will be a legitimate finding in its own right and increase our understanding.

Due to limitations of resources it will not be possible to accommodate potential participants who are unable to comprehend written English and the materials will not be translated into any other language. As the primary method of advertisement will be via written materials it is perhaps unlikely that this will be problematic in terms of denying an interested and eligible person the ability to participate. It will, however, mean the sample is unlikely to represent those with the lowest levels of literacy. This limitation is common to much research.

In order to offer some protection against this, participants with specific access or literacy requirements will be able to contact the researcher to request large print versions of the materials or for the researcher to read the items out to them over the phone and record their response themselves (in which case written consent will be requested via hard copy or email or if that is not possible the researcher will read the PIS and consent form to the participant verbatim and take verbal consent over the phone).

A convenience sample of those that meet the eligibility criteria will be sought. Reaching populations who have a visible difference can be challenging and the most fruitful avenue is often via support groups and charities that have an interest in the area and whose members may have a visible difference. These will include groups whose interest is in visible difference per se (i.e. Changing Faces) as well as a variety of condition specific groups (i.e. CLAPA).

The study will therefore be advertised by a combination of: CAR's social media and internet pages; sending information to CAR's mailing list (of people that have consented to receive information about the center and its activities); a UWE press release; and the social media, newsletters and web-pages of support groups, charities and other organisations whose members may be interested in participating and who agree to do so. The researcher will liaise with a number of partner groups in facilitating this and will hope to advertise via the seventeen organisations that advertised the qualitative study together with any others that agree to do so. Participants will not be placed under any pressure to take part as their involvement will be entirely contingent upon their response to an advertisement. The researcher will also seek to take advantage of any opportunities that may present themselves to advertise the study (presentations, talks, media engagement).

The researcher has become aware of the Prolific Academic website. This is an Oxford University Innovation Startup Incubator company which acts as a mechanism for registered researchers to access Prolific Academic's registered participants, offers a prescreening facility, directs participants to the study (on Qualtrics) and deals with paying participants who complete the study and whose responses are approved by the researcher. The researcher is investigating this service and the study may therefore be made available via Prolific Academic and in that event minor amendments will be made to the documentation used for relevant participants to reflect that those entering it via Prolific will not receive the Amazon voucher but will get payment via that mechanism

instead (this may mean creating a second Qualtrics site identical to the first in all other respects – this will also help with the separate administration relating to the two routes into the study). In all other respects the documentation and study requirements will be the same as those who are not recruited through Prolific Academic. No additional data will be provided to UWE or within Qualtrics by any participants accessing the study via Prolific Academic and those persons will have, by definition, already agreed to the Prolific Academic terms which are consistent with this activity (and govern the separate relationship between Prolific and the individual)

The study will be hosted by the Qualtrics site and Participants will therefore be able to take part in the study with minimal involvement from or contact with the researcher and will be able to do so anonymously (with identifiable or contact data only being collected from those that wish to receive the thank you gift and shall be used only for that purpose). The various advertisements for the study are (depending upon the requirements of the relevant partner or body advertising) likely to include a brief description of the study, the researcher's contact details and a link to the Qualtrics site. This link is the participants' primary method of accessing the study, reading the full information, consenting and taking part. Any paper documentation (see below) will mirror and mimic the online version.

The anticipated recruitment methods will afford priority and primacy to on-line methods of advertisement and participation. Again, this may influence the composition of the sample but convenience, costs, resources and opportunities dictate that this is likely to remain an issue. Whilst, once more, this limitation may be common with other research, the researcher will remain alive to any possibility to advertise the research via alternative means. Such opportunities may arise once contact is made with the various partner organisations and so are difficult to predict. Similarly, paper copies of the study documentation will be available upon request and the researcher can post these to individual participants that request them or provide a number of them to partner organisations to make available to their members (and others). In these instances the researcher will procure pre-paid self-addressed envelopes to minimize any cost or inconvenience to participants.

Determining an appropriate sample size for this research and with which to conduct an exploratory factor analysis of the measure is a somewhat contentious matter. Some literature (such as and as summarized by Pett, Lackey and Sullivan, 2003) advocates attempting to recruit a specific number of participants (10-15) per variable (or item). Fortunately the recruitment of that number of participants is not necessarily required as others (i.e. Clark and Watson, 1995) consider it possible to specify an absolute number, in their case 300. This figure of 300 is highlighted by others (Tabachnik and Fidell, 2013); Field, 2013) as being a sensible sample size that should ordinarily provide a stable factor solution. The reason that this number may only be specified with some hesitation is that, as Field (2013) summarises, the number of items that load onto each factor and the loadings of the individual items onto the factor together with the communalities (a measure of the common variance explained by each variable or, essentially, how it correlates with all other items/factors), can impact the required sample size. Sample size is less important (and so can be smaller) with a greater number of loadings, with greater loading values and with higher communalities.

Despite these issues and uncertainties (the loadings and communalities cannot be ascertained until after data has been collected), the aim will be to recruit 300 participants to ensure a satisfactory sample size. This may be considered a challenging or ambitious target but it is hoped that the ability to advertise with and recruit from multiple charities and organisations, the interest shown in the earlier (perhaps more personally demanding) qualitative study (with some 200 persons accessing on-line information about the study), the possibility of utilizing Prolific Academic in recruitment, the legitimacy of opening up the study to a non-visible difference population if required and the ability to offer a voucher-code as a small thank you will all contribute to make this realistic. If the goal of 300 is not achieved then it is still possible that an equally valid analysis can be performed, though this may depend a little more on the nature of the data.

As is evident from this discussion, the number of items that load onto each factor may be critical to determining an adequate sample size and so the initial items have been drafted to ensure that at least four items may be expected to load onto each thematic / theoretical domain. This is because Field (2013) cites evidence (Guadagnoli and Velicer, 1998) that a factor has four if more items with loadings of greater than 0.6 then it may be considered reliable, irrespective of sample size.

5. What are your arrangements for obtaining informed consent whether written, verbal or other? (where applicable, copies of participant information sheets and consent forms should be provided)

*Informed consent is an ethical requirement of most research. Applicants should demonstrate that they are conversant with and have given due consideration to the need for informed consent and that any consent forms prepared for the study ensure that potential research participants are given sufficient information about a study, in a format they understand, to enable them to exercise their right to make an informed decision whether or not to participate in a research study.*

*You should describe how you will obtain informed consent from the participants and, where this is written consent, include copies of participant information sheets and consent forms. Where other forms of consent are obtained (eg verbal, recorded) you should explain the processes you intend to use. If you do not intend to seek consent or are using covert methods, you need to explain and justify your approach. Please consider carefully whether or not you need to seek consent for archiving or re-use of data.*

The on-line and (if and when utilized) paper versions of the scale and related measures will be preceded by the participant information sheet (attached in appendix) which contains full details of the study, consent form (attached in appendix) and eligibility confirmation. These will all require a response in order for participants to proceed so that those that do not indicate that they have read and understood the PIS and provided the necessary consent to are not able to take part in the study and no further data will therefore be collected in this instance. Hard copy versions will be checked upon receipt and the data only entered into the study if the consent form has been completed by the participant). It is anticipated that this will provide a robust consent process so that only

<p>those who have had the opportunity to read the study documentation, who are eligible, who consent in accordance with the consent form and who confirm all of this to be so will participate.</p> <p>Whilst the on-line version will seek such confirmation, the paper version will require the consent form marked by the participant. In the event of any participant wishing to participate via the researcher reading the items to them over the phone, this will be preceded by the researcher reading, verbatim, the PIS, eligibility criteria and consent form. Participants will be asked to provide their verbal consent which will be recorded by the researcher on a hard copy of the consent form.</p>
<p>6. What arrangements are in place for participants to withdraw from the study?</p>
<p><i>Consent must be freely given with sufficient detail to indicate what participating in the study will involve and how they may withdraw. There should be no penalty for withdrawing and the participant is not required to provide any reason.</i></p> <p><i>Please note: allowing participants to withdraw at any time could prejudice your ability to complete your research. It may be appropriate to set a fixed final withdrawal date.</i></p>
<p>Participants will be required (as part of the demographics form, attached in appendix) to generate a code so that their data may be withdrawn from the study upon their request. This will help ensure the anonymity of the data and the PIS and consent form reflect participants' right to withdraw from the study up to four weeks after first accessing Qualtrics site if performed on-line and up-to four weeks after receipt of any hard copy versions by the researcher.</p> <p>In accordance with the PIS and consent form, should they wish to withdraw their data from the study participants will be required to contact the researcher by phone or email within the four week period, quoting their participation identification code. This will enable the researcher to identify the material that needs to be deleted due to their withdrawal from the project and to disregard this data in the analyses of the results. A four week period has been specified as withdrawal will not be possible once the data are published, presented or otherwise made public.</p>
<p>7. If the research generates personal data, please describe the arrangements for maintaining anonymity and confidentiality (or the reasons for not doing so)</p>
<p><i>You should explain what measures you plan to take to ensure that the information provided by research participants is anonymised/pseudonymised (where appropriate) and how it will be kept confidential. In the event that the data are not to be anonymised/pseudonymised, please provide a justification.</i></p> <p><i>Personal data is defined as 'personal information about a living person which is being, or which will be processed as part of a relevant filing system. This personal information includes for example, opinions, photographs and voice recordings' (UWE Data Protection Act 1998, Guidance for Employees).</i></p>
<p>The data collected will be anonymous in nature, participants will not be asked to provide their name or other information from which the researcher may identify them as this is not required (and may also help to reduce any social desirability effects) and will indicate their consent by ticking a box within Qualtrics site or marking a hard copy of the consent</p>

form if a paper version is used. The link between the individual and their data will be the participant information code they generate and this will need to be resupplied to the researcher if any participant wishes to withdraw their data. This will ensure anonymity as the researcher will not have access to identifiable information.

The data will not be confidential in nature in that summary aggregated and analysed data will be published and made publically available. The raw data, however, will be accessed only by the researcher and those colleagues involved in the study (as reflected in the PIS and consent form) and whilst the data may be presented according to participant demographics it is not envisaged that individual responses will be published in full or individually associated with the demographic data provided in any publication or presentation.

It is intended to offer participants a thank you gift. Amazon vouchers of £10 denomination will be provided to participants (or, if the Prolific Academic site is used then a similar payment will be made in respect of each participant and Prolific will pay those participants cash via its chosen method, pay-pal, instead of a voucher-code being provided). To be eligible for this each participant will need to provide a phone number or email address. They will then be contacted by the researcher and provided with the voucher code. Nothing need be physically sent to the participant so their address will not be required. Any details provided in connection with this (beyond the contact details which will be in the Qualtrics site / hard copy documentation - for example if the participant provides a phone number but asks on the phone for the code to be emailed) will be stored only on the UWE email servers or in hard copy in a locked cabinet and will not be connected to the substantive study data nor will the contact details or any subsequent information provided in connection with the vouchers be published or otherwise distributed. Any additional information provided will be deleted or destroyed once the voucher has been provided. Participation in this process is entirely voluntarily and participants are able to decline the opportunity if they wish and choose not to provide any contact details.

8. Please describe how you will store data collected in the course of your research and maintain data Security and protection.

*Describe how you will store the data, who will have access to it, and what happens to it at the end of the project, including any arrangements for long-term storage of data and potential re-use. If your research is externally funded, the research sponsors may have specific requirements for retention of records. You should consult the terms and conditions of grant awards for details.*

***It may be appropriate for the research data to be offered to a data archive for re-use. If this is the case, it is important that consent for this is included in the participant consent form.***

*UWE IT Services provides data protection and encryption facilities - see [http://www.uwe.ac.uk/its-staff/corporate/ourpolicies/intranet/encryption\\_facilities\\_provided\\_by\\_uwe\\_itservices.shtml](http://www.uwe.ac.uk/its-staff/corporate/ourpolicies/intranet/encryption_facilities_provided_by_uwe_itservices.shtml) !*

It is not anticipated that personally identifiable data will be routinely collected, though this is possible if the contact details provided for the thank you gift render an individual identifiable. The primary method of identifying an individual if, for example, they wish to withdraw their data, will be via the individual providing their participant identification code (comprised of the first two letters of their first name, the day on the month on which they were born and the first two letters of the name of their first school). Being able to provide this will be taken as evidence that an individual has the right to withdraw their data. They will, however, not be given access to the data that is withdrawn as it is possible it may belong to another person and the match is a chance coincidence or the result of them knowing the relevant information about a participant. This is because to secure anonymity and as it is not necessary to collect them, the study team will not have the names of participants or any way to decode the participant identification code or validate the identity of anyone wishing to withdraw data.

The study data will be stored on the password Qualtrics site (which the researcher understands has been approved by UWE for the use in research for data protection purposes under a compatible site license) and will (as above) contain a minimal amount of personally identifiable data. When it is ported into SPSS for the purpose of analysis any contact details provided for the thank you gift will not be ported or will immediately be deleted so that the SPSS data does not contain personally identifiable information. Though they will not contain personally identifiable information, the SPSS data files will be stored on the 'h:' drive or the researcher's personal drive within UWE's secure, password protected system and servers.

Any hard copy study data will be stored in a locked cabinet in the office used by the researcher (currently 2L13). This room is routinely locked when not occupied and is dedicated to members of CAR (and occasional visitors).

Study data will be accessed only by the study team and its collaborators (as per the PIS and consent form).

The study data will be securely stored and saved for five years (in line with the regulations stated by the British Psychological Society). After five years the data will be destroyed.

Contact details and information provided in connection with the thank you gift will be accessed only by the study team (the researcher and supervisors) and anything beyond that provided on Qualtrics site will be deleted or destroyed once it is no longer required for those purposes.

9. What risks (eg physical, psychological, social, legal or economic), if any, do the participants face in taking part in this research and how will you Address these risks?

*Describe ethical issues related to the physical, psychological and emotional wellbeing of the participants, and what you will do to protect their wellbeing. If you do not envisage there being any risks to the participants, please make it clear that you have considered the possibility and justify your approach.*

A risk assessment has been undertaken (attached) and, as this demonstrates, few significant risks are anticipated in connection with this work. It is possible that responding

to some of the items may lead to some level of distress as this is a potentially sensitive or uncomfortable topic but participants will be informed of the nature of the study (via the PIS) and will not be obligated to answer any individual item (on the scale under development or the associated measures) and will have the option to bypass or omit any item they do not wish to answer. Participants will be free to discontinue their participation at any moment and will not be in the physical presence of the researcher so are unlikely to feel compelled to continue if they do not wish to do so.

The associated measures have been validated and used in previous research with no indication that distress, anxiety or discomfort has been experienced by participants in that research. None of the items (in the scale under development or associated ones) are graphic, explicit or likely to be deemed offensive. The scale items have been generated by the researcher based primarily on a high quality qualitative study, have been reviewed by the supervisory team (including the DoS) and a (now semi-retired) research active clinical psychologist who was instrumental in identifying this area as one in need of research and will be reviewed by other members of CAR prior to the study being opened. This robust process acts to ensure that offence and harm is unlikely to result from the nature of the (newly developed) items.

The researcher and DoS contact details will be available on the final page of the study documentation as well as the PIS in case participants have any comments or complaints. Links to lists of support groups covering both appearance related concern, appearance altering conditions and mental health and which are maintained by Changing Faces and the Centre for Appearance Research are provided in the information sheet and again at the end of the study as part of the debrief in case participants require further information or contact details of relevant organisations.

The high level of anonymity and minimal level of personal information that is being requested as part of this study makes it low risk from a data protection standpoint. Participants will be asked to provide their time in completing the research scales and to access the internet (if this is how they participate) at their own expense. A realistic estimate of the time commitment is provided on the PIS and the costs associated with accessing the internet are not considered excessive as it is considered unlikely that those who do not have this access will seek it specifically to participate.

In recognition of these inconveniences and as a thank you for the time commitment, however, participants will each be provided with a £10 Amazon voucher code or similar (described above). It is anticipated that this will not result in anyone taking part in a study that requires a not in considerable input of time and attention when they would otherwise have not been prepared to do so. It is not anticipated that the thank you will influence the responses in any way as (aside from contact details) participation is anonymous. Qualtrics data (such as time spent on the site) will be utilized to ensure (so far as possible) that participants are genuine and only one voucher code will be provided to any one email address / phone.

10. Are there any potential risks to researchers and any other people impacted by this study as a consequence of undertaking this Research that are greater than those encountered in

normal day to day life?
<p><i>Describe any health and safety issues including risks and dangers for both the participants and yourself (if appropriate) and what you will do about them. This might include, for instance, arrangements to ensure that a supervisor or co-researcher has details of your whereabouts and a means of contacting you when you conduct interviews away from your base; or ensuring that a 'chaperone' is available if necessary for one-to-one interviews. Please check to confirm you have carried out a risk assessment for your research</i> <input type="checkbox"/></p>
It is not anticipated that this research will involve any risks other than those identified in section 9.
11. How will the results of the research be reported and disseminated?
<p><i>Please indicate in which forms and formats the results of the research will be communicated.</i></p> <p><b>(Select all that apply)</b></p> <p><input checked="" type="checkbox"/> Peer reviewed journal</p> <p><input checked="" type="checkbox"/> Conference presentation</p> <p><input type="checkbox"/> Internal report</p> <p><input checked="" type="checkbox"/> Dissertation/Thesis</p> <p><input type="checkbox"/> Other publication</p> <p><input type="checkbox"/> Written feedback to research participants</p> <p><input type="checkbox"/> Presentation to participants or relevant community groups</p> <p><input type="checkbox"/> Digital Media</p> <p><input type="checkbox"/> Other (Please specify below)</p>
12. WILL YOUR RESEARCH BE TAKING PLACE OVERSEAS?
<p><i>If you intend to undertake research overseas, please provide details of additional issues which this may raise, and describe how you will address these. Eg language, culture, legal framework, insurance, data protection, political climate, health and safety. Please also clarify whether or not ethics approval will be sought locally in another country.</i></p>
no
13. Are there any other ethical issues that have not been addressed which you would wish to bring to the attention of the Faculty and/or University Research Ethics Committee?
<p><i>This gives the researcher the opportunity to raise any other ethical issues considered in planning the research or which the researcher feels need raising with the Committee.</i></p>

The original qualitative study that the researcher has conducted was performed partly in anticipation of the development of this scale and that was communicated to the participants in that study. It is thus arguable that there is an ethical duty owed to those original participants to proceed with this work.

## CHECKLIST

**Please complete before submitting the form**

**Please note: supporting documentation should include version numbers and dates**

	Yes/No
Is a copy of the research proposal attached?	n/a
Have you explained how you will select the participants?	Yes
Is a participant information sheet attached?	Yes
Is a participant consent form attached?	Yes
Is a copy of your questionnaire/topic guide attached?	Yes
Have you described the ethical issues related to the well-being of participants?	Yes
Have you described fully how you will maintain confidentiality?	Yes
Have you included details of data protection including data storage?	Yes
Where applicable, is evidence of a current DBS (formerly CRB) check attached?	n/a
Is a Risk Assessment form attached? (HAS only)	Yes
Have you considered health and safety issues for the participants and researchers?	Yes

## DECLARATION

**The information contained in this application, including any accompanying information, is to the best of my knowledge, complete and correct. I have attempted to identify all risks related to the research that may arise in conducting this research and acknowledge my obligations and the right of the participants.**

Principal Investigator name	Nicholas Sharratt
Signature	NDS
Date	23.01.2017
Supervisor or module leader name (where appropriate)	Nichola Rumsey
Signature	NR
Date	20.01.2017

The signed form should be submitted electronically to Committee Services: [researchethics@uwe.ac.uk](mailto:researchethics@uwe.ac.uk) and email copied to the Supervisor/Director of Studies where applicable together with all supporting documentation (research proposal, participant information sheet, consent form etc).

For student applications where an electronic signature is not available from the Supervisor we will require an email from the Supervisor confirming support.

Please provide all the information requested and justify where appropriate.

For further guidance, please see <http://www1.uwe.ac.uk/research/researchethics> (applicants' information)

## Appendix B6: EFA: University of the West of England General Risk Assessment Form



### GENERAL RISK ASSESSMENT FORM

Ref: HAS/15/03/132

<b>Describe the activity being assessed:</b>  Questionnaire study to be conducted on-line / via paper copies related to visible difference and romantic intimate relationships	<b>Assessed by:</b>  Nicholas Sharratt	<b>Endorsed by:</b>  Professor Nichola Rumsey
<b>Who might be harmed: Participants</b>  <b>How many exposed to risk:</b> <span style="border: 1px solid black; padding: 2px;">Approx 250</span>	<b>Date of Assessment:</b>  09/01/2017	<b>Review date(s):</b>  01/02/2018 if project is ongoing, it's likely to be under 12 months in duration

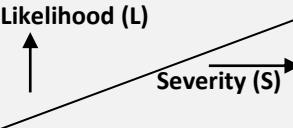
Hazards Identified (state the potential harm)	Existing Control Measures	S	L	Risk Level	Additional Control Measures	S	L	Risk Level	By whom and by when	Date completed
(Participant- human/ behavioural factors) stress, discomfort and distress due to the sensitive nature and content of the questionnaire items	Prior to the study participants will be informed about the general issues and topics covered in the research - it is likely that those participants who may be at a heightened risk of distress/ detrimental effects will choose not to participate  Participant's right to withdraw from the	2	2	4	A link to lists of sources of support and links to relevant organisations and charities is being provided to participants in the information sheet and at the end of the study  The study does not require that identifying information be provided	1	2	2	Researcher Upon request	

	<p>study at any time and for any reason will be emphasized at the beginning of the study. Similarly, participants will be informed that they do not have to answer any particular item. It is up to the individual participant to make an informed choice as to whether they carry on or stop the study</p> <p>The existing measures used have been used and validated in previous published research with no indication that they caused significant distress. The items have been reviewed by the researcher for suitability and appropriateness</p> <p>The items generated for the new scale have been drafted with this risk in mind and the aim was to ensure that they are sensitively worded. They have been reviewed by the researcher, the supervisory team (including Professor Nichola Rumsey and Dr Liz Jenkinson, a registered Health Psychologist) and a (semi-retired) research active Clinical Psychologist</p>				<p>(though is needed in the form of an email address or phone number if the participant wishes to enter the thank you draw) and so participants can avoid any distress associated with their name or other identifying information being associated with their responses and can therefore participate entirely anonymously if they desire</p>					
(Data – regulatory / legal issues) distress caused by data being processed otherwise than in accordance with the DPA	Participants are not being asked for information from which they can be identified. Their names will only be provided to the extent that they are incorporated in their email address (which may voluntarily be provided if they wish to enter a small thank you prize draw)	2	1	2						

		Data will be stored on and accessed via secure UWE servers and any hard copies kept in a locked cabinet on Uwe premises								
		The researcher has sought confirmation that the provider of the on-line survey tool is compliant with the DPA								
		The participant information sheet and consent form that will be displayed to and agreed by all participants outlines the use that will be made of the data								
(Participant- physical discomfort)		<p>The study will primarily be conducted on-line and is estimated to take 25-30 minutes to complete. This will involve the use of a VDU and keyboard / mouse (or equivalent) by participants. This may have implications for postural and visual health, though the requirement and participation is a one off event.</p> <p>These risks, however, are considered within the bounds of those encountered in daily life and it is considered likely that those who participate on-line will be regular computer users and able to regulate their own use of the equipment. The Health and Safety Executive uses an example of a break of 5-10 minutes after 50-60 minutes use. The study should not take that long to complete and whilst it is possible that participants may have been</p>	1	2	2					

	using the equipment before they begin this is out of the researcher's control and the inclusion of a specific warning or reminder is considered and adjudged unnecessary in these circumstances.									
--	--	--	--	--	--	--	--	--	--	--

**RISK MATRIX: (To generate the risk level).**

Very likely 5	5	10	15	20	25
Likely 4	4	8	12	16	20
Possible 3	3	6	9	12	15
Unlikely 2	2	4	6	8	10
Extremely unlikely 1	1	2	3	4	5
Likelihood (L)  Severity (S)	Minor injury – No first aid treatment required 1	Minor injury – Requires First Aid Treatment 2	Injury - requires GP treatment or Hospital attendance 3	Major Injury 4	Fatality 5

**ACTION LEVEL: (To identify what action needs to be taken).**

POINTS:	RISK LEVEL:	ACTION:
1 – 2	NEGLIGIBLE	No further action is necessary.
3 – 5	TOLERABLE	Where possible, reduce the risk further

6 - 12	MODERATE	Additional control measures are required
15 – 16	HIGH	Immediate action is necessary
20 - 25	INTOLERABLE	Stop the activity/ do not start the activity

**Appendix B7: EFA: University of the West of England Faculty of Health and  
Applied Sciences: Faculty Research Ethics Committee Approval Letter**



**Faculty of Health &  
Applied  
Sciences  
Glenside Campus  
Blackberry Hill  
Stapleton  
Bristol BS16 1DD**

**Tel: 0117 328 1170**

UWE REC REF No: HAS.17.01.092

24<sup>th</sup> February 2017

Nicholas Sharratt  
UWE  
Room 2L13  
Frenchay Campus

Dear Nicholas

**Application title: Questionnaire study to be conducted on-line / via paper copies related  
to visible difference and romantic intimate relationships**

Your ethics application was considered by the Faculty Research Ethics Committee and, based on the information provided, has been given ethical approval to proceed. There are a couple of suggestions that have been made but these are not conditions of approval.

1. On the Information Sheet – please use the new brand UWE logo
2. On the Information Sheet there are 2 unedited hyperlinks to organisations that provide support. I would suggest editing these so that they show as the name of the organisation rather than a long hyperlink.

You must notify the committee in advance if you wish to make any significant amendments to the original application using the amendment form at

<http://www1.uwe.ac.uk/research/researchethics/applyingforapproval.aspx>

Please note that any information sheets and consent forms should have the UWE logo. Further guidance is available on the web:

<http://www1.uwe.ac.uk/aboutus/departmentsandservices/professionalservices/marketingandcommunications/resources.aspx>

The following standard conditions also apply to all research given ethical approval by a UWE Research Ethics Committee:

1. You must notify the relevant UWE Research Ethics Committee in advance if you wish to make significant amendments to the original application: these include any changes to the study protocol which have an ethical dimension. Please note that any changes approved by an external research ethics committee must also be communicated to the relevant UWE committee.

2. You must notify the University Research Ethics Committee if you terminate your research before completion;
3. You must notify the University Research Ethics Committee if there are any serious events or developments in the research that have an ethical dimension.

Please note: The UREC is required to monitor and audit the ethical conduct of research involving human participants, data and tissue conducted by academic staff, students and researchers. Your project may be selected for audit from the research projects submitted to and approved by the UREC and its committees.

Please remember to populate the HAS Research Governance Record with your ethics outcome via the following link: <https://teams.uwe.ac.uk/sites/HASgovernance>.

We wish you well with your research.

Yours sincerely

Dr Julie Woodley  
Chair  
Faculty Research Ethics Committee

c.c. Professor Nichola Rumsey

## **Appendix B8: EFA: Participant Information Sheet**

**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.

#### **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.

#### **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.

#### **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.

#### **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.

#### **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.

### **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)

### **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.

### **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.

### **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).

### **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.

### **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.

#### **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](mailto: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:

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

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

## Appendix B9: EFA Consent Form

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



### ***‘Visible Differences, Intimacy and Romantic Intimate Relationships’ (the ‘Study’)***

#### **PARTICIPANT CONSENT FORM AND DATA PROTECTION NOTICE**

**I confirm that:**

	Please tick or otherwise mark to indicate your consent
1. I am 18 years of age or over and live or am based in the UK or Ireland	<input type="checkbox"/>
2. I understand that I should not participate if I have a diagnosed mental health condition which is currently uncontrolled by medication or intervention and which has a significant impact upon the activities of daily living. I do not have such a condition	<input type="checkbox"/>
3. I have read the information sheet for the Study (version 1.1 dated 29/11/2017), I understand it and I have had the opportunity to contact the research team and ask them any questions that I have about it	<input type="checkbox"/>
4. I understand that taking part in this study will involve me completing a short questionnaire exploring my experiences and feelings related to visible difference, intimacy and sexual activity	<input type="checkbox"/>
5. I understand that I can chose not to answer any question I do not want to answer	<input type="checkbox"/>
6. I understand that I can withdraw my participation in the Study at any time and without providing any reason for doing so by ceasing to complete the questionnaire. If I do withdraw my participation in this way, I understand that any data I have already provided may be used unless I expressly withdraw it from the study during the period specified in this consent form	<input type="checkbox"/>
7. I understand that I may withdraw my data from the study but am only able to do so during the four week period immediately following the date upon which I provide that information. If I wish to withdraw my data I must contact the researcher and provide my participant code (generated below)	<input type="checkbox"/>
8. I agree to the University of the West Of England processing my	<input type="checkbox"/>

personal data as described in the Data Protection Notice within the information sheet for the study (version 1.1 dated 29/11/2017)	
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**I agree to all the above and I agree to participate in the Study:**

<input type="checkbox"/>	
<b>Please tick, cross or make any other mark to indicate your consent</b>	<b>Date</b>

In order for your data to be stored securely and so that we can identify it should you wish to withdraw from the study, we need to generate a code. Please provide:

<b>The first two letters of your first name (i.e. 'ni'):</b>	
<b>The day of the month on which you were born (i.e. '17'):</b>	
<b>The first two letters of the name of your first school (i.e. 'ru'):</b>	

If you would like to be entered into a draw for one of a number of £10 Amazon voucher codes as a thank you for your proper and attentive participation then please provide a UK phone number (mobile or landline) and an email address so that you may be contacted in connection with your participation and a code can be sent to you if you are successful in the draw.

Please note that we are unable to provide an Amazon voucher (even if you are successful in the draw) if you do not provide a UK phone number on which you can be contacted.

<b>Email address</b>

<b>UK phone number</b>

**Appendix C1: EFA: CARRIS 49 Items: Eigenvalues and Percentage of Variance Explained**

Appendix C1

*EFA CARRIS: 49 Items, 253 Participants: Eigenvalues and Variance Explained*

Factor Number.	Eigenvalue	% of Variance Explained	Cumulative % of Variance Explained
1	16.737	34.158	34.158
2	3.205	6.542	40.699
3	2.284	4.662	45.361
4	1.920	3.917	49.278
5	1.757	3.585	52.864
6	1.463	2.985	55.849
7	1.348	2.751	58.600
8	1.174	2.396	60.996
9	1.118	2.282	63.278
10	1.011	2.063	65.341
11	.956	1.951	67.291
12	.894	1.824	69.115
13	.835	1.704	70.820
14	.790	1.613	72.432
15	.745	1.520	73.953
16	.718	1.465	75.417
17	.686	1.401	76.818

18	.651	1.328	78.146
19	.632	1.290	79.437
20	.606	1.237	80.674
21	.581	1.185	81.859
22	.567	1.158	83.017
23	.545	1.111	84.128
24	.512	1.045	85.173
25	.487	.993	86.167
26	.484	.987	87.154
27	.458	.935	88.089
28	.436	.889	88.979
29	.423	.863	89.842
30	.396	.808	90.650
31	.352	.719	91.369
32	.343	.700	92.069
33	.328	.670	92.739
34	.319	.652	93.391
35	.315	.642	94.033
36	.302	.616	94.650
37	.296	.605	95.254
38	.269	.550	95.804
39	.247	.504	96.308
40	.235	.480	96.788

41	.232	.473	97.260
42	.219	.448	97.708
43	.208	.425	98.133
44	.200	.408	98.541
45	.168	.342	98.883
46	.155	.317	99.201
47	.142	.290	99.490
48	.136	.277	99.767
49	.114	.233	100.000

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## Appendix C2: EFA: CARRIS 49 Items: Pattern Matrix: 5 Factor Solution

### Appendix C2

*EFA CARRIS: 49 Items (variables), 253 Participants (cases): Pattern Matrix (loadings suppressed at <.1*

CARRIS Item	F1	F2	F 3	F4	F5
(22) I have a reduced desire for sexual activity because of my appearance	.786				
(64) The prospect of sexual contact makes me feel uncomfortable	.768				
(24) I would avoid undressing in front of a partner	.701				
(32) I avoid certain sexual activity because of how I look	.686				
(54) I would avoid sexual activity with an established partner because of my appearance	.655				
(23) I feel comfortable when a partner touches my body in a sexual manner	.639				
(7) I would feel comfortable being naked in front of my partner	.638				
(60) I would avoid sexual activity with a new partner because of how I look	.551				
(52) I feel discomfort at being seen naked by a partner	.535		.363		
(66) I would postpone engaging in sexual activity with a new partner because of how I look	.527	.362			
(8) I engage in less sexual activity than I would otherwise because of my appearance	.507				
(33) I am able to relax and fully enjoy	.480				

sexual activity		
(72) Receiving the romantic attention of another person would make me feel anxious	.453	
(53) I would alter my sexual behaviour because of how I look	.443	.375
(68) During sexual activity, I would use clothing, lighting or choose certain positions to hide aspects of my appearance	.380	.358
(3) I would reject the romantic approach of another person	.379	
(61) A potential new partner would judge my appearance negatively	.766	
(1) My attractiveness to others is limited by my appearance	.709	
(29) My appearance is an extra barrier to me developing romantic relationships	.694	
(70) A new partner would be put off me by my appearance	.683	
(62) I would be worried about telling a potential or new partner about my appearance	.669	
(42) It would take someone special to accept me as a partner	.649	
(35) Other people are repelled by my appearance	.599	
(28) I would find it difficult to choose a picture of myself to present to potential partners	.549	
(31) I need to put extra effort into my relationships because of how I look	.507	.439
(17) I would be lucky to find a partner who accepts me for who I am	.500	
(43) A partner would feel little sexual	.482	

desire for me		
(30) I would withhold my feelings about how I look from a partner	.392	.355
(36) It is normal for people like me to be single	.386	
(9) A partner of mine would be embarrassed or ashamed to be seen with me in public	.352	
(59) I feel anxious immediately prior to sexual activity	.692	
(45) I feel anxious during sexual activity	.690	
(14) During sexual activity I think about what my partner can see	.629	
(69) I feel comfortable with my appearance in sexual situations	.456	
(67) I am satisfied with my intimate and romantic life	.387	
(11) I find it difficult to talk to people that I am attracted to	.366	
(38) The romantic or sexual interest of others in me is genuine	.364	.362
(51) I grow apart from my partners or experience conflict in my relationships because of my appearance	.333	
(12) I would feel able to openly discuss my appearance with a partner		.727
(46) My partner could understand how I feel about my appearance		.596
(71) My partner would be able to provide me with support and comfort if I felt unhappy about how I look		.592
(57) Speaking about how I look with a partner would be a positive		.583

experience		
(65) I would know how to speak to a new partner about my appearance		.418
(20) Discussing my appearance with a partner would make me less attractive to them		.351
(10) I would know when to tell a new partner about my appearance		
(48) Other people are physically attracted to me		.653
(6) Other people find me sexually attractive		.561
(56) I feel physically attractive	.352	.475
(63) I would approach someone that I was attracted to		

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Arranged by primary Factor and in order of descending loadings

Extraction Method: Principal Axis Factoring

Rotation Method: Promax

Rotation converged in 13 iterations

**Appendix C3: EFA: CARRIS 36 Items: Eigenvalues and Percentage of Variance Explained**

Appendix C3

*EFA CARRIS: 36 Items, 253 Participants: Eigenvalues and Variance Explained*

Factor Number.	Eigenvalue	% of Variance Explained	Cumulative % of Variance Explained
1	13.641	37.891	37.891
2	2.883	8.009	45.900
3	2.054	5.707	51.607
4	1.443	4.008	55.615
5	1.349	3.747	59.362
6	1.019	2.830	62.192
7	.990	2.751	64.943
8	.972	2.701	67.644
9	.849	2.357	70.001
10	.759	2.107	72.108
11	.693	1.925	74.033
12	.673	1.870	75.904
13	.646	1.794	77.698
14	.621	1.724	79.422
15	.580	1.610	81.032
16	.505	1.403	82.435
17	.494	1.373	83.808
18	.492	1.366	85.174
19	.474	1.316	86.490
20	.445	1.235	87.725
21	.420	1.166	88.891
22	.413	1.147	90.038
23	.377	1.047	91.085
24	.362	1.007	92.091
25	.327	.908	92.999

26	.306	.851	93.850
27	.294	.816	94.666
28	.278	.773	95.439
29	.264	.733	96.172
30	.258	.716	96.888
31	.249	.691	97.579
32	.214	.596	98.174
33	.188	.522	98.696
34	.174	.482	99.178
35	.160	.445	99.623
36	.136	.377	100.000

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#### Appendix C4: EFA: CARRIS 36 Items: Pattern Matrix: 3 Factor Solution

##### Appendix C4

*EFA CARRIS: 36 Items (variables), 253 Participants (cases): Pattern Matrix (loadings suppressed at <.1*

CARRIS Item	F1	F2	F3
(59) I feel anxious immediately prior to sexual activity	.802	-.172	
(52) I feel discomfort at being seen naked by a partner	.792		.107
(45) I feel anxious during sexual activity	.769	-.111	
(24) I would avoid undressing in front of a partner	.766	-.180	.177
(53) I would alter my sexual behaviour because of how I look	.725	.144	-.129
(32) I avoid certain sexual activity because of how I look	.712	.168	
(22) I have a reduced desire for sexual activity because of my appearance	.656		
(23) I feel comfortable when a partner touches my body in a sexual manner	.651	-.212	.223
(33) I am able to relax and fully enjoy sexual activity	.650		.209
(60) I would avoid sexual activity with a new partner because of how I look	.615	.249	-.122
(64) The prospect of sexual contact makes me feel uncomfortable	.606	.173	
(14) During sexual activity I think about what my partner can see	.602		
(8) I engage in less sexual activity than I would otherwise because of my appearance	.598	.181	-.100
(69) I feel comfortable with my appearance in sexual situations	.596		.161
(7) I would feel comfortable being naked in front of my partner	.588	-.112	.339
(66) I would postpone engaging in sexual activity with a new partner because of how I look	.587	.358	-.217
(54) I would avoid sexual activity with an established partner because of my appearance	.583		

(72) Receiving the romantic attention of another person would make me feel anxious	.299	.290	.169
(61) A potential new partner would judge my appearance negatively		.796	
(1) My attractiveness to others is limited by my appearance	-.146	.740	
(70) A new partner would be put off me by my appearance	.136	.733	-.103
(29) My appearance is an extra barrier to me developing romantic relationships	.180	.673	
(62) I would be worried about telling a potential or new partner about my appearance	.205	.660	-.184
(35) Other people are repelled by my appearance		.644	
(43) A partner would feel little sexual desire for me		.615	.233
(28) I would find it difficult to choose a picture of myself to present to potential partners	-.170	.609	.210
(42) It would take someone special to accept me as a partner		.606	-.191
(56) I feel physically attractive	-.108	.560	.276
(17) I would be lucky to find a partner who accepts me for who I am		.536	
(48) Other people are physically attracted to me		.460	.318
(6) Other people find me sexually attractive		.457	.353
(65) I would know how to speak to a new partner about my appearance		.310	.239
(71) My partner would be able to provide me with support and comfort if I felt unhappy about how I look			.599
(12) I would feel able to openly discuss my appearance with a partner		.176	.543
(57) Speaking about how I look with a partner would be a positive experience			.510
(46) My partner could understand how I feel about my appearance			.504

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Arranged by primary Factor and in order of descending loadings

Extraction Method: Principal Axis Factoring

Rotation Method: Promax

Rotation converged in 7 iterations

**Appendix C5: EFA: CARRIS 34 Items: Eigenvalues and Percentage of Variance Explained**

Appendix C5

*EFA CARRIS: 34 Items, 253 Participants: Eigenvalues and Variance Explained*

Factor Number.	Eigenvalue	% of Variance Explained	Cumulative % of Variance Explained
1	13.009	38.263	38.263
2	2.860	8.413	46.676
3	2.032	5.976	52.651
4	1.417	4.167	56.818
5	1.262	3.711	60.529
6	.989	2.909	63.438
7	.970	2.853	66.291
8	.899	2.643	68.934
9	.827	2.433	71.367
10	.697	2.050	73.417
11	.665	1.957	75.374
12	.645	1.898	77.272
13	.620	1.822	79.094
14	.596	1.753	80.847
15	.518	1.524	82.371
16	.498	1.465	83.836
17	.480	1.411	85.247
18	.460	1.353	86.600
19	.442	1.301	87.900
20	.419	1.231	89.132
21	.394	1.158	90.290
22	.379	1.114	91.404
23	.336	.988	92.392
24	.321	.944	93.336
25	.313	.920	94.256
26	.288	.847	95.104
27	.266	.784	95.887
28	.263	.774	96.661
29	.257	.757	97.419

30	.215	.632	98.051
31	.190	.557	98.608
32	.174	.512	99.120
33	.163	.479	99.599
34	.136	.401	100.000

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## Appendix C6: EFA: CARRIS 34 Items: Pattern Matrix: 3 Factor Solution

### Appendix C6

*EFA CARRIS: 34 Items (variables), 253 Participants (cases): Pattern Matrix (loadings suppressed at <.1*

CARRIS Item	F1	F2	F3
(59) I feel anxious immediately prior to sexual activity	.788	-.165	
(52) I feel discomfort at being seen naked by a partner	.785		.121
(24) I would avoid undressing in front of a partner	.759	-.172	.186
(45) I feel anxious during sexual activity	.758	-.103	
(53) I would alter my sexual behaviour because of how I look	.719	.145	-.112
(32) I avoid certain sexual activity because of how I look	.711	.169	
(22) I have a reduced desire for sexual activity because of my appearance	.654		
(23) I feel comfortable when a partner touches my body in a sexual manner	.650	-.205	.219
(33) I am able to relax and fully enjoy sexual activity	.646		.220
(60) I would avoid sexual activity with a new partner because of how I look	.619	.245	-.125
(64) The prospect of sexual contact makes me feel uncomfortable	.604	.168	
(14) During sexual activity I think about what my partner can see	.602		
(69) I feel comfortable with my appearance in sexual situations	.593		.175
(8) I engage in less sexual activity than I would otherwise because of my appearance	.592	.182	
(66) I would postpone engaging in sexual activity with a new partner because of how I look	.592	.348	-.221
(7) I would feel comfortable being naked in front of my partner	.583	-.104	.354
(54) I would avoid sexual activity with an established partner because of my appearance	.580		

(61) A potential new partner would judge my appearance negatively		.784	
(1) My attractiveness to others is limited by my appearance	-.133	.730	.109
(70) A new partner would be put off me by my appearance	.147	.722	
(29) My appearance is an extra barrier to me developing romantic relationships	.187	.666	
(62) I would be worried about telling a potential or new partner about my appearance	.223	.644	-.193
(35) Other people are repelled by my appearance		.638	
(43) A partner would feel little sexual desire for me		.611	.246
(28) I would find it difficult to choose a picture of myself to present to potential partners	-.163	.605	.227
(42) It would take someone special to accept me as a partner		.595	-.173
(56) I feel physically attractive	-.102	.555	.293
(17) I would be lucky to find a partner who accepts me for who I am		.529	
(48) Other people are physically attracted to me		.461	.349
(6) Other people find me sexually attractive		.457	.379
(71) My partner would be able to provide me with support and comfort if I felt unhappy about how I look			.582
(12) I would feel able to openly discuss my appearance with a partner	.105	.176	.497
(46) My partner could understand how I feel about my appearance			.488
(57) Speaking about how I look with a partner would be a positive experience			.481

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Arranged by primary Factor and in order of descending loadings

Extraction Method: Principal Axis Factoring

Rotation Method: Promax

Rotation converged in 7 iterations

### Appendix C7: EFA: CARRIS 34 Items: Item Retention and Deletion Decisions

#### Appendix C7

#### EFA: CARRIS 34 items: Item Retention and Deletion Decisions

Item (no) and text	Factor	Loading	Cross Loadings	Distribution	Meaning	Decision (reasons for deletion)
(59) <i>I feel anxious immediately prior to sexual activity</i>	1	.788	<.1 1-.2	Good-OK	Sexual anxiety - anticipatory	Include
(52) <i>I feel discomfort at being seen naked by a partner</i>	1	.785	<.1 .1-.2	OK-Good (some –ive skew)	Naked anxiety	Include
(24) <i>I would avoid undressing in front of a partner</i>	1	.759	.1-.2 .1-.2	Good-OK	Partner shame body	Include
(45) <i>I feel anxious during sexual activity</i>	1	.758	<.1 .1-.2	Good-OK	Sexual activity - anxiety	Include

<i>(53) I would alter my sexual behaviour because of how I look</i>	1	.719	.1-.2 .1-.2	Good-OK	Sexual activity - alter	Include
<i>(32) I avoid certain sexual activity because of how I look</i>	1	.711	<.1 .1-.2	OK-Good	Sexual activity - avoidance	Include
<i>(22) I have a reduced desire for sexual activity because of my appearance</i>	1	.654	<.1 <.1	OK	Sexual desire - reduced	Discard (distribution, encompassed by items 53, 32)
<i>(23) I feel comfortable when a partner touches my body in a sexual manner (x)</i>	1	.650	.2-.3 .2-.3	OK-Good	Sexual touch - discomfort	Discard (cross loadings, encompassed by item 33)
<i>(33) I am able to relax</i>	1	.646	1 <.1	Good-OK	Sexual discomfort	Include

<i>and fully enjoy sexual activity (x)</i>			.2-.3	(flat)		
<i>(60) I would avoid sexual activity with a new partner because of how I look</i>	1	.619	.1-.2 .2-.3	Good	Sexual activity – avoid (new partner)	Discard (encompassed by item 32, relative loadings & cross loadings)
<i>(64) The prospect of sexual contact makes me feel uncomfortable</i>	1	.604	<.1 1-.2	Good	Sexual discomfort - anticipatory	Discard (encompassed by item 59, relative loading)
<i>(14) During sexual activity I think about what my partner can see</i>	1	.602	<.1 <.1	Poor (ive skew)	Sexual self-consciousness	Discard (distribution, encompassed by items 45, 53, 32, 33, 69 relative loading)
<i>(69) I feel comfortable with my appearance in</i>	1	.593	<.1 .1-.2	OK-Good (+ive skew)	Sexual self-consciousness	Include

<i>sexual situations (x)</i>						
<i>(8) I engage in less sexual activity than I would otherwise because of my appearance</i>	1	.592	<.1 .1-.2	Good-OK	Sexual activity - reduce	Discard (encompassed by items 53, 32,. relative loading)
<i>(66) I would postpone engaging in sexual activity with a new partner because of how I look</i>	1	.592	.2-.3 .32-.4	OK-Good	Sex activity – delay (new partner)	Discard (cross loadings)
<i>(7) I would feel comfortable being naked in front of my partner (x)</i>	1	.583	.1-.2 .32-.4	Good	Naked - comfort	Discard (cross loadings, encompassed by item 52)
<i>(54) I would avoid sexual activity with an</i>	1	.580	<.1 <.1	Poor	Sex activity – avoid established partner	Discard (encompassed by item

<i>established partner because of my appearance</i>						32, distribution)
<i>(61) A potential new partner would judge my appearance negatively</i>	2	.784	<.1 <.1	Poor (-ive skew)	Negative judgment – new partner	Discard (distribution, encompassed by item 70)
<i>(1) My attractiveness to others is limited by my appearance</i>	2	.730	.1-.2 .1-.2	Poor (-ive skew)	Unattractive to others	Discard (distribution, encompassed by ) (covered by items 35, 70, relative cross loadings)
<i>(70) A new partner would be put off by my appearance</i>	2	.722	<.1 .1-.2	Good	Negative judgement – new partner	Include
<i>(29) My appearance is</i>	2	.666	<.1	Poor	Devalued – barrier	Include

<i>an extra barrier to me developing romantic relationships</i>			.1-.2		to relationships	
<i>(62) I would be worried about telling a potential or new partner about my appearance</i>	2	.644	.1-.2 .2-.3	Poor	Disclosure – new partner	Include
<i>(35) Other people are repelled by my appearance</i>	2	.638	<.1 <.1	Good - OK	Negative judgement – others	Include
<i>(43) A partner would feel little sexual desire for me</i>	2	.611	<.1 .2-.3	Good	Sexually unattractive	Include
<i>(28) I would find it difficult to choose a</i>	2	.605	.1-.2 .2-.3	Poor	Disclosure	Discard (distribution,

<i>picture of myself to present to potential partners</i>						encompassed by item 62, relative cross loading)
<i>(42) It would take someone special to accept me as a partner</i>	2	.595	<.1 .1-.2	Poor	Devalued – someone special to accept	Discard (distribution, encompassed by item 29)
<i>(56) I feel physically attractive (x)</i>	2	.555	.1-.2 .2-.3	OK	Attractive	Include
<i>(17) I would be lucky to find a partner who accepts me for who I am</i>	2	.529	<.1 <.1	Poor	Devalued - lucky	Discard (distribution, encompassed by item 29, relative loading)
<i>(48) Other people are physically attracted to</i>	2	.461	1 < .1 32-.4	Good-OK	Attractive to others	Discard (cross loading, low

<i>me (x)</i>						loading to cross loading difference, encompassed by items 56, 35)
<i>(6) Other people find me sexually attractive (x)</i>	2	.457	1 < .1 .32-.4	Good	Attractive to others	Discard (cross loading, low loading to cross loading difference, encompassed by items 56, 35)
<i>(71) My partner would be able to provide me with support and comfort if I felt unhappy about how I look (x)</i>	3	.582 (3)	<.1 <.1	Poor	Access partner support	Include
<i>(12) I would feel able</i>	3	.497 (3)	.1-.2	Good-OK	Openness to partner	Include

<i>to openly discuss my appearance with a partner (x)</i>			.1-.2			
(46) <i>My partner could understand how I feel about my appearance (x)</i>	3	.488 (3)	<.1 <.1	Poor	Partner Understanding	Include
(57) <i>Speaking about how I look with a partner would be a positive experience (x)</i>	3	.481 (3)	<.1 <.1	Good-OK	Closeness	Include

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**Appendix C8: EFA: CARRIS 18 Items: Eigenvalues and Percentage of Variance Explained**

Appendix C8

*EFA CARRIS: 18 Items, 253 Participants: Eigenvalues and Variance Explained*

Factor Number.	Eigenvalue	% of Variance Explained	Cumulative % of Variance Explained
1	7.381	41.006	41.006
2	1.824	10.135	51.141
3	1.665	9.247	60.388
4	.906	5.032	65.420
5	.898	4.989	70.410
6	.665	3.697	74.107
7	.621	3.450	77.557
8	.580	3.224	80.780
9	.534	2.965	83.746
10	.504	2.798	86.544
11	.438	2.432	88.976
12	.426	2.365	91.342
13	.349	1.940	93.282
14	.321	1.782	95.064
15	.289	1.608	96.672
16	.222	1.235	97.907
17	.204	1.133	99.040
18	.173	.960	100.000

## Appendix C9: EFA: CARRIS 18 Items: Pattern Matrix: 3 Factor Solution

### Appendix C9

*EFA CARRIS: 18 Items (variables), 253 Participants (cases): Pattern Matrix (loadings suppressed at <.1*

CARRIS Item	F1	F2	F3
(45) I feel anxious during sexual activity	.864	-.159	
(59) I feel anxious immediately prior to sexual activity	.863	-.170	
(52) I feel discomfort at being seen naked by a partner	.778		
(24) I would avoid undressing in front of a partner	.704		
(69) I feel comfortable with my appearance in sexual situations	.677		
(53) I would alter my sexual behaviour because of how I look	.674	.217	-.140
(33) I am able to relax and fully enjoy sexual activity	.610		
(32) I avoid certain sexual activity because of how I look	.550	.359	
(70) A new partner would be put off me by my appearance		.931	-.129
(62) I would be worried about telling a potential or new partner about my appearance		.749	-.130
(35) Other people are repelled by my appearance	-.143	.695	
(43) A partner would feel little sexual desire for me		.607	.229
(29) My appearance is an extra barrier to me developing romantic relationships	.188	.601	
(56) I feel physically attractive		.579	.106
(12) I would feel able to openly discuss my appearance with a partner		.188	.656
(71) My partner would be able to provide me with support and comfort if I felt unhappy about how I look			.647
(46) My partner could understand how I feel about my appearance		-.123	.646

(57) Speaking about how I look with a partner would be a positive experience	.106	.501
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Arranged by primary Factor and in order of descending loadings

Extraction Method: Principal Axis Factoring

Rotation Method: Promax

Rotation converged in 5 iterations

**Appendix C10: EFA: CARRIS 17 Items: Eigenvalues and Percentage of Variance Explained**

Appendix C10

*EFA CARRIS: 17 Items, 253 Participants: Eigenvalues and Variance Explained*

Factor Number.	Eigenvalue	% of Variance Explained	Cumulative % of Variance Explained
1	6.787	39.925	39.925
2	1.814	10.669	50.594
3	1.643	9.667	60.262
4	.899	5.289	65.550
5	.886	5.215	70.765
6	.661	3.890	74.655
7	.610	3.586	78.241
8	.563	3.309	81.550
9	.532	3.128	84.678
10	.483	2.839	87.517
11	.434	2.554	90.072
12	.390	2.297	92.369
13	.321	1.891	94.259
14	.301	1.773	96.033
15	.289	1.700	97.732
16	.210	1.235	98.968
17	.175	1.032	100.000

## Appendix C11: EFA: CARRIS 17 Items: Pattern Matrix: 3 Factor Solution

### Appendix C11

*EFA CARRIS: 17 Items (variables), 253 Participants (cases): Pattern Matrix (loadings suppressed at <.1*

CARRIS Item	F1	F2	F3
(59) I feel anxious immediately prior to sexual activity	.869	-.136	
(45) I feel anxious during sexual activity	.867	-.128	
(52) I feel discomfort at being seen naked by a partner	.760		
(69) I feel comfortable with my appearance in sexual situations	.677		
(24) I would avoid undressing in front of a partner	.676		
(53) I would alter my sexual behaviour because of how I look	.645	.233	-.126
(33) I am able to relax and fully enjoy sexual activity	.584	.113	.104
(70) A new partner would be put off me by my appearance		.935	-.147
(62) I would be worried about telling a potential or new partner about my appearance		.740	-.130
(35) Other people are repelled by my appearance	-.124	.688	
(29) My appearance is an extra barrier to me developing romantic relationships	.193	.602	
(43) A partner would feel little sexual desire for me		.600	.225
(56) I feel physically attractive		.576	
(12) I would feel able to openly discuss my appearance with a partner		.173	.668
(46) My partner could understand how I feel about my appearance		-.135	.661
(71) My partner would be able to provide me with support and comfort if I felt unhappy about how I look			.651
(57) Speaking about how I look with a partner would be a positive experience			.503

Arranged by primary Factor and in order of descending loadings

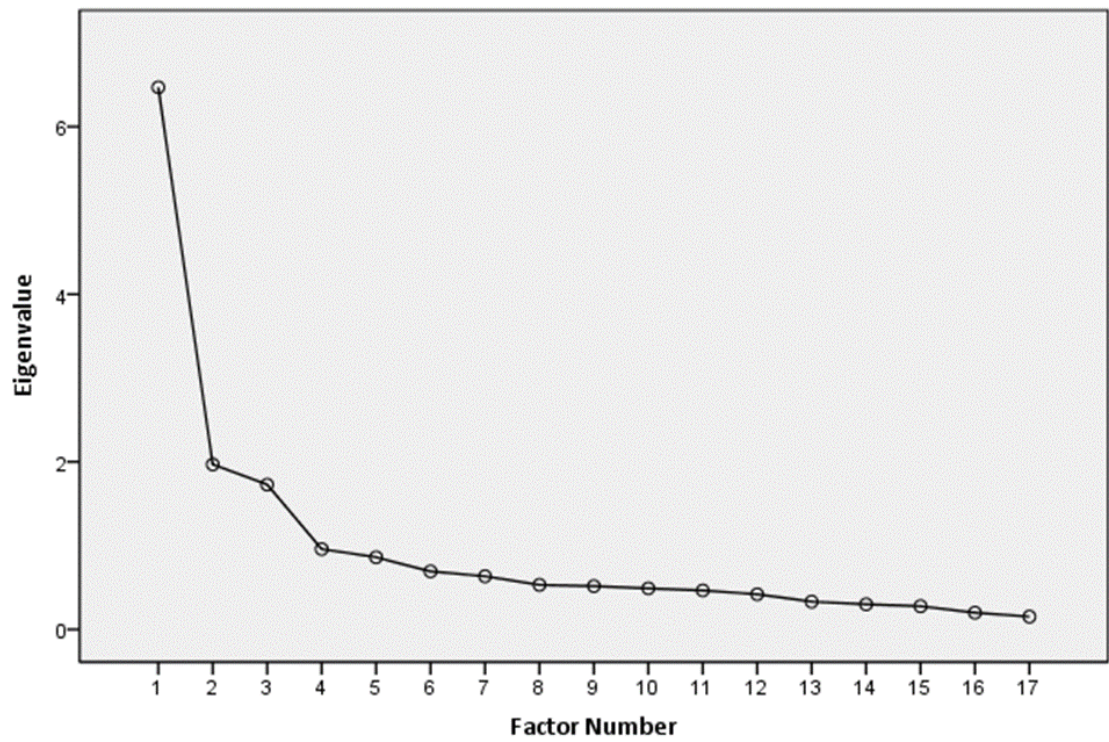
Extraction Method: Principal Axis Factoring

Rotation Method: Promax

Rotation converged in 5 iterations

# Appendix D1: EFA: CARRIS 17 Items: Female Participants Scree Plot

Appendix D1: EFA: Scree Plot: Female Participants



**Appendix D2: EFA: CARRIS 17 Items: Female Participants: Eigenvalues and  
Percentage of Variance Explained**

Appendix D2

*EFA CARRIS: Female Participants: 17 Items, 168 Participants: Eigenvalues and Variance Explained*

Factor Number.	Eigenvalue	% of Variance Explained	Cumulative % of Variance Explained
1	6.469	38.054	38.054
2	1.969	11.581	49.635
3	1.728	10.162	59.797
4	.959	5.642	65.439
5	.862	5.068	70.507
6	.693	4.076	74.583
7	.634	3.732	78.315
8	.532	3.127	81.441
9	.518	3.045	84.486
10	.490	2.883	87.369
11	.465	2.737	90.106
12	.420	2.472	92.578
13	.332	1.950	94.528
14	.300	1.766	96.294
15	.277	1.631	97.925
16	.200	1.176	99.100
17	.153	.900	100.000

### Appendix D3: EFA: CARRIS 17 Items: Female Participants: Pattern Matrix: 3

#### Factor Solution

Appendix D3

*EFA CARRIS: Female Participants 17 Items (variables), 168 Participants (cases): Pattern Matrix (loadings suppressed at <.32)*

CARRIS Item	F1	F2	F3
(59) I feel anxious immediately prior to sexual activity	.861		
(45) I feel anxious during sexual activity	.845		
(52) I feel discomfort at being seen naked by a partner	.775		
(24) I would avoid undressing in front of a partner	.696		
(53) I would alter my sexual behaviour because of how I look	.672		
(33) I am able to relax and fully enjoy sexual activity	.642		
(69) I feel comfortable with my appearance in sexual situations	.580		
(70) A new partner would be put off me by my appearance		.965	
(62) I would be worried about telling a potential or new partner about my appearance		.660	
(35) Other people are repelled by my appearance		.655	
(43) A partner would feel little sexual desire for me		.598	
(56) I feel physically attractive		.568	
(29) My appearance is an extra barrier to me developing romantic relationships		.563	
(46) My partner could understand how I feel about my appearance			.714
(12) I would feel able to openly discuss my appearance with a partner			.710
(71) My partner would be able to provide me with support and comfort if I felt unhappy about how I look			.706
(57) Speaking about how I look with a partner would be a positive experience			.511

Arranged by primary Factor and in order of descending loadings

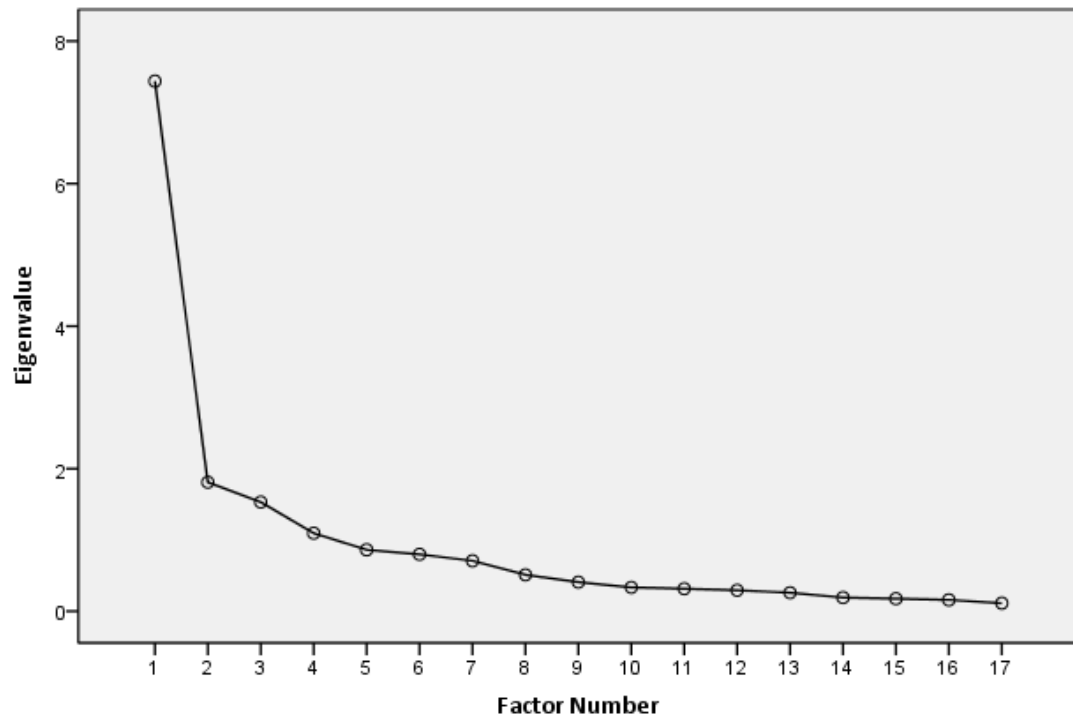
Extraction Method: Principal Axis Factoring

Rotation Method: Promax

Rotation converged in 5 iterations

#### Appendix D4: EFA: CARRIS 17 Items: Male Participants Scree Plot

Appendix D4: EFA: Scree Plot: Male Participants



**Appendix D5: EFA: CARRIS 17 Items: Male Participants Eigenvalues and  
Percentage of Variance Explained**

Appendix D5

*EFA CARRIS: Male Participants 17 Items, 75 Participants: Eigenvalues and Variance Explained*

Factor Number.	Eigenvalue	% of Variance Explained	Cumulative % of Variance Explained
1	7.438	43.754	43.754
2	1.809	10.643	54.397
3	1.531	9.008	63.405
4	1.095	6.441	69.846
5	.861	5.065	74.911
6	.798	4.694	79.606
7	.707	4.157	83.762
8	.511	3.006	86.768
9	.407	2.397	89.165
10	.334	1.964	91.129
11	.316	1.857	92.986
12	.294	1.728	94.714
13	.261	1.533	96.247
14	.191	1.125	97.372
15	.176	1.033	98.404
16	.159	.936	99.340
17	.112	.660	100.000

**Appendix D6: EFA: CARRIS 17 Items: Male Participants Pattern Matrix: 3 Factor  
Solution**

Appendix D6

*EFA CARRIS: Male Participants 17 Items (variables), 75 Participants (cases): Pattern Matrix  
(loadings suppressed at <.1*

CARRIS Item	F1	F2	F3
(62) I would be worried about telling a potential or new partner about my appearance	.979		
(70) A new partner would be put off me by my appearance	.802		
(29) My appearance is an extra barrier to me developing romantic relationships	.709		
(35) Other people are repelled by my appearance	.652		.333
(56) I feel physically attractive	.621		
(53) I would alter my sexual behaviour because of how I look	.529	.477	
(43) A partner would feel little sexual desire for me	.466		.343
(33) I am able to relax and fully enjoy sexual activity	.394		
(69) I feel comfortable with my appearance in sexual situations		.873	
(45) I feel anxious during sexual activity		.829	
(59) I feel anxious immediately prior to sexual activity		.799	
(52) I feel discomfort at being seen naked by a partner	.365	.566	
(24) I would avoid undressing in front of a partner		.527	
(12) I would feel able to openly discuss my appearance with a partner			.816
(71) My partner would be able to provide me with support and comfort if I felt unhappy about how I look		.384	.446
(57) Speaking about how I look with a partner would be a positive experience			.428

(46) My partner could understand how I feel about  
my appearance

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.419

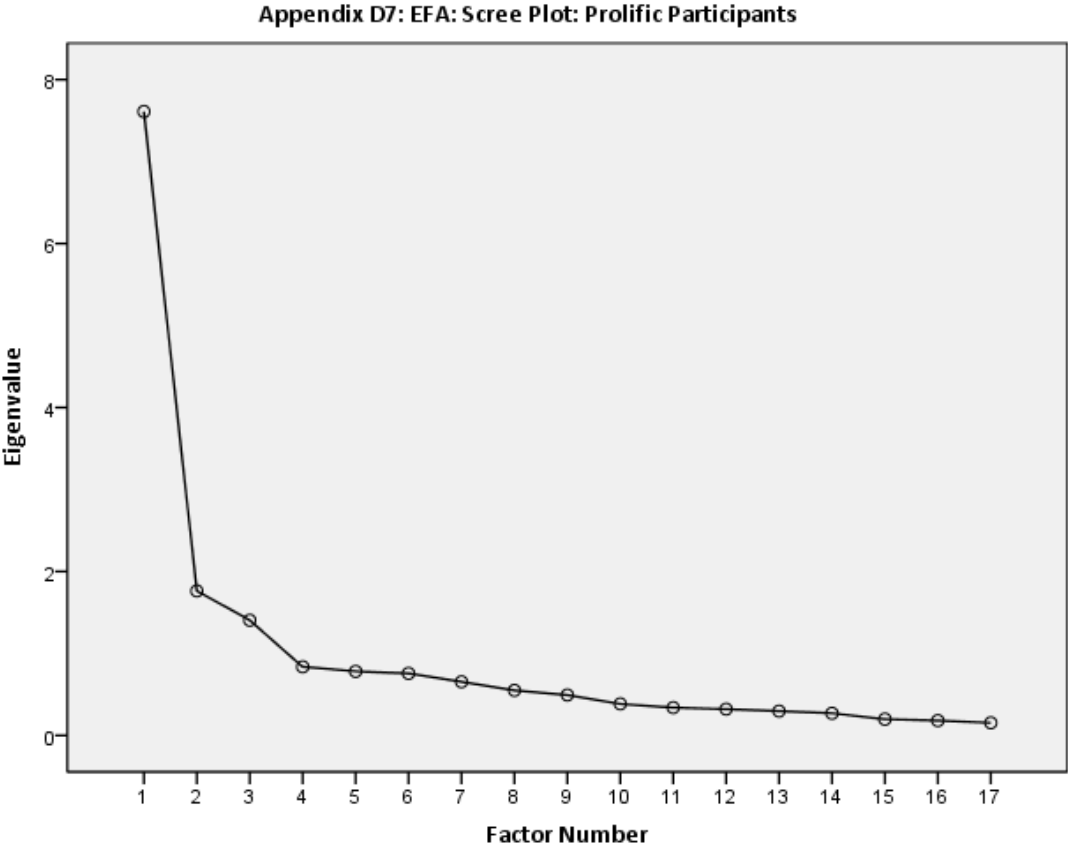
Arranged by primary Factor and in order of descending loadings

Extraction Method: Principal Axis Factoring

Rotation Method: Promax

Rotation converged in 7 iterations

Appendix D7: EFA: CARRIS 17 Items: Prolific Participants Scree Plot



**Appendix D8: EFA: CARRIS 17 Items: Prolific Participants: Eigenvalues and  
Percentage of Variance Explained**

Appendix D8

*EFA CARRIS: Prolific Participants 17 Items, 138 Participants: Eigenvalues and Variance Explained*

Factor Number.	Eigenvalue	% of Variance Explained	Cumulative % of Variance Explained
1	7.611	44.768	44.768
2	1.763	10.369	55.137
3	1.406	8.269	63.406
4	.837	4.925	68.331
5	.782	4.599	72.930
6	.757	4.453	77.383
7	.654	3.850	81.232
8	.550	3.236	84.469
9	.493	2.902	87.371
10	.385	2.262	89.633
11	.339	1.995	91.628
12	.321	1.890	93.518
13	.297	1.750	95.268
14	.271	1.592	96.860
15	.198	1.167	98.028
16	.182	1.069	99.096
17	.154	.904	100.000

## Appendix D9: EFA: CARRIS 17 Items: Prolific Participants: Pattern Matrix: 3

### Factor Solution

Appendix D9

*EFA CARRIS: Prolific Participants: 17 Items (variables), 138 Participants (cases): Pattern Matrix (loadings suppressed at <.32*

CARRIS Item	F1	F2	F3
(70) A new partner would be put off me by my appearance	.827		
(62) I would be worried about telling a potential or new partner about my appearance	.790		
(43) A partner would feel little sexual desire for me	.761		
(29) My appearance is an extra barrier to me developing romantic relationships	.748		
(35) Other people are repelled by my appearance	.693		
(56) I feel physically attractive	.578		
(45) I feel anxious during sexual activity		.839	
(69) I feel comfortable with my appearance in sexual situations		.819	
(59) I feel anxious immediately prior to sexual activity		.808	
(52) I feel discomfort at being seen naked by a partner		.772	
(24) I would avoid undressing in front of a partner		.725	
(53) I would alter my sexual behaviour because of how I look	.391	.540	
(33) I am able to relax and fully enjoy sexual activity		.494	
(12) I would feel able to openly discuss my appearance with a partner			.706
(46) My partner could understand how I feel about my appearance			.661
(71) My partner would be able to provide me with support and comfort if I felt unhappy about how I look			.546

(57) Speaking about how I look with a partner would  
be a positive experience

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.440

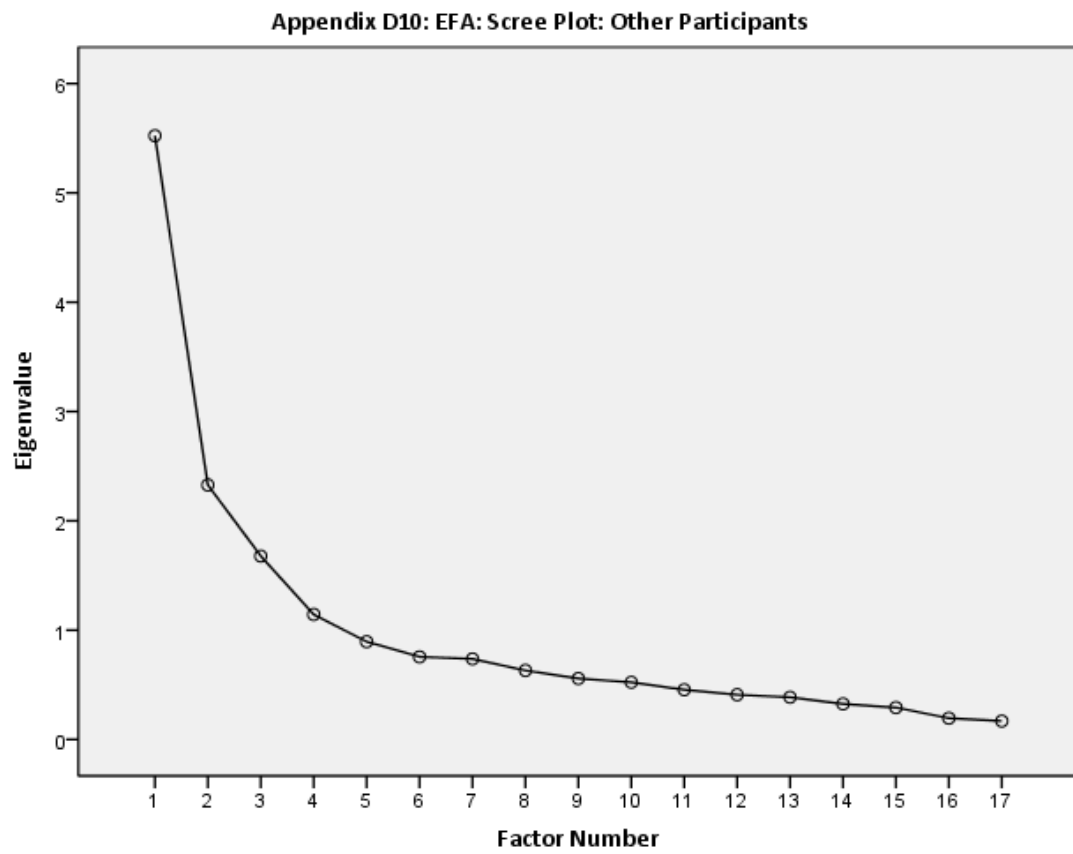
Arranged by primary Factor and in order of descending loadings

Extraction Method: Principal Axis Factoring

Rotation Method: Promax

Rotation converged in 6 iterations

## Appendix D10: EFA: CARRIS 17 Items: Other Participants Scree Plot



**Appendix D11: EFA: CARRIS 17 Items: Other Participants: Eigenvalues and  
Percentage of Variance Explained**

Appendix D11

*EFA CARRIS: Other Participants: 17 Items, 104 Participants: Eigenvalues and Variance Explained*

Factor Number.	Eigenvalue	% of Variance Explained	Cumulative % of Variance Explained
1	5.523	32.490	32.490
2	2.328	13.693	46.183
3	1.678	9.869	56.052
4	1.143	6.726	62.778
5	.894	5.262	68.040
6	.756	4.445	72.485
7	.737	4.335	76.820
8	.631	3.710	80.531
9	.558	3.280	83.811
10	.523	3.075	86.886
11	.455	2.674	89.560
12	.409	2.405	91.964
13	.386	2.271	94.235
14	.325	1.914	96.149
15	.292	1.716	97.865
16	.194	1.143	99.008
17	.169	.992	100.000

## Appendix D12: EFA: CARRIS 17 Items: Other Participants: Pattern Matrix: 3

### Factor Solution

Appendix D12

*EFA CARRIS: Other Participants: 17 Items (variables), 104 Participants (cases): Pattern Matrix (loadings suppressed at <.32*

CARRIS Item	F1	F2	F3
(45) I feel anxious during sexual activity	.821		
(59) I feel anxious immediately prior to sexual activity	.815		
(52) I feel discomfort at being seen naked by a partner	.740		
(53) I would alter my sexual behaviour because of how I look	.696		
(24) I would avoid undressing in front of a partner	.618		
(33) I am able to relax and fully enjoy sexual activity	.602		
(69) I feel comfortable with my appearance in sexual situations	.580		
(70) A new partner would be put off me by my appearance		1.011	
(56) I feel physically attractive		.648	
(62) I would be worried about telling a potential or new partner about my appearance		.585	
(35) Other people are repelled by my appearance		.552	
(43) A partner would feel little sexual desire for me		.421	
(29) My appearance is an extra barrier to me developing romantic relationships			
(46) My partner could understand how I feel about my appearance			.770
(71) My partner would be able to provide me with support and comfort if I felt unhappy about how I look			.681
(12) I would feel able to openly discuss my appearance with a partner			.637
(57) Speaking about how I look with a partner would be a positive experience			.470

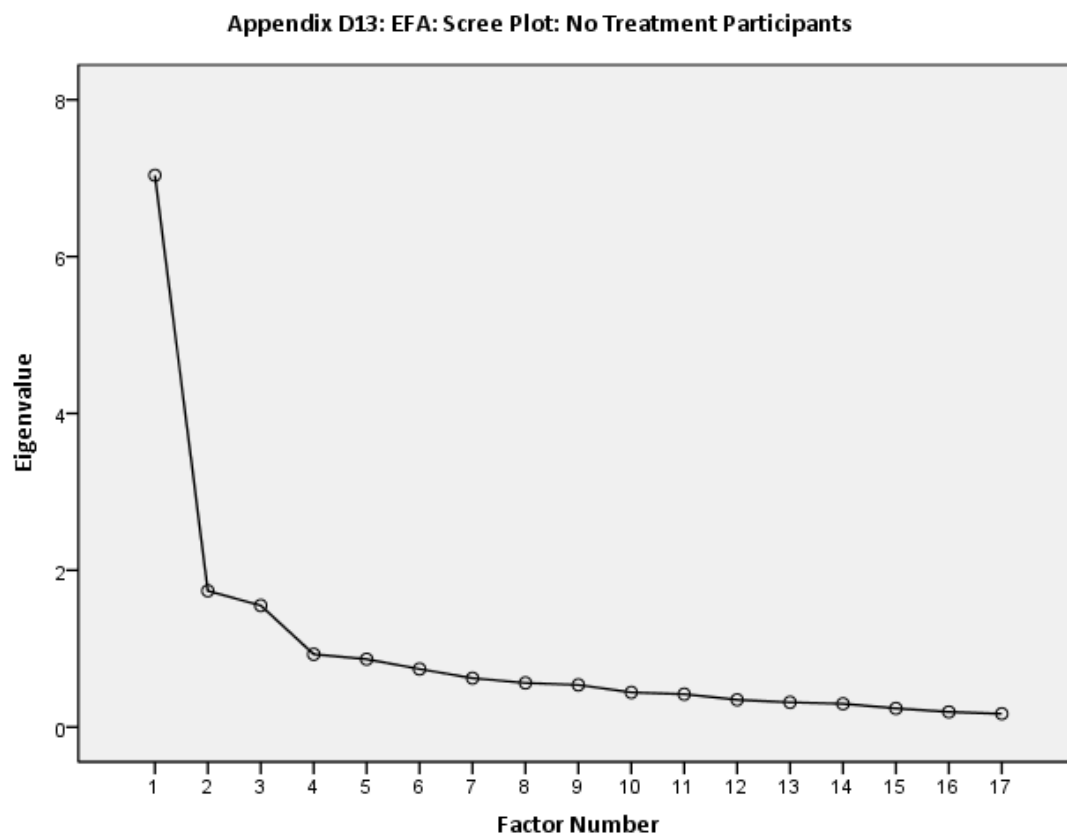
Arranged by primary Factor and in order of descending loadings

Extraction Method: Principal Axis Factoring

Rotation Method: Promax

Rotation converged in 5 iterations

### Appendix D13: EFA: CARRIS 17 Items: No Treatment Participants Scree Plot



**Appendix D14: EFA: CARRIS 17 Items: No Treatment Participants: Eigenvalues  
and Percentage of Variance Explained**

Appendix D14

*EFA CARRIS: No Treatment: 17 Items, 159 Participants: Eigenvalues and Variance Explained*

Factor Number.	Eigenvalue	% of Variance Explained	Cumulative % of Variance Explained
1	7.037	41.392	41.392
2	1.737	10.218	51.610
3	1.550	9.117	60.727
4	.928	5.460	66.187
5	.865	5.091	71.278
6	.740	4.350	75.628
7	.624	3.668	79.296
8	.562	3.307	82.602
9	.538	3.162	85.764
10	.442	2.599	88.363
11	.419	2.466	90.830
12	.347	2.043	92.873
13	.315	1.852	94.725
14	.296	1.743	96.469
15	.238	1.397	97.866
16	.193	1.136	99.002
17	.170	.998	100.000

**Appendix D15: EFA: CARRIS 17 Items: No Treatment Participants: Pattern  
Matrix: 3 Factor Solution**

Appendix D15

*EFA CARRIS: No Treatment Participants: 17 Items (variables), 159 Participants (cases):  
Pattern Matrix (loadings suppressed at <.32*

CARRIS Item	F1	F2	F3
(59) I feel anxious immediately prior to sexual activity	.846		
(52) I feel discomfort at being seen naked by a partner	.830		
(45) I feel anxious during sexual activity	.812		
(24) I would avoid undressing in front of a partner	.749		
(53) I would alter my sexual behaviour because of how I look	.661		
(69) I feel comfortable with my appearance in sexual situations	.545		
(33) I am able to relax and fully enjoy sexual activity	.492		
(70) A new partner would be put off me by my appearance		.860	
(62) I would be worried about telling a potential or new partner about my appearance		.772	
(43) A partner would feel little sexual desire for me		.771	
(29) My appearance is an extra barrier to me developing romantic relationships		.610	
(56) I feel physically attractive		.603	
(35) Other people are repelled by my appearance		.544	
(71) My partner would be able to provide me with support and comfort if I felt unhappy about how I look			.698
(46) My partner could understand how I feel about my appearance			.672
(12) I would feel able to openly discuss my appearance with a partner			.600

(57) Speaking about how I look with a partner would  
be a positive experience

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.504

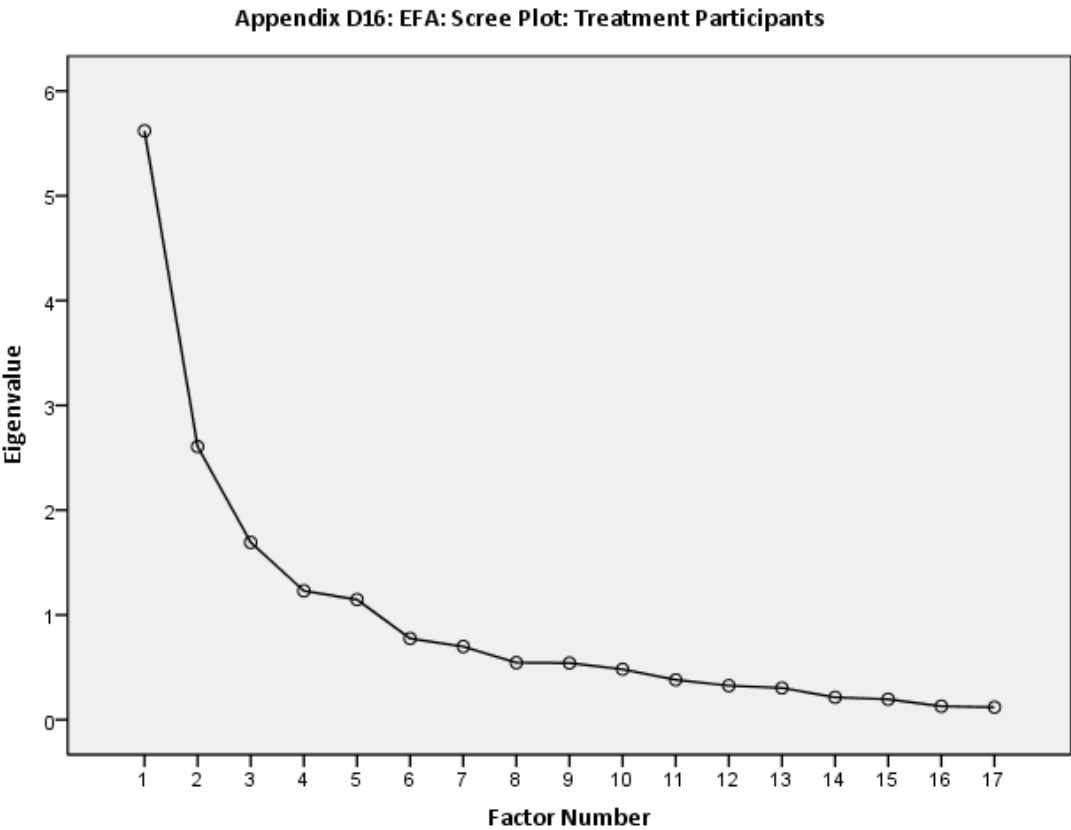
Arranged by primary Factor and in order of descending loadings

Extraction Method: Principal Axis Factoring

Rotation Method: Promax

Rotation converged in 5 iterations

Appendix D16: EFA: CARRIS 17 Items: Treatment Participants Scree Plot



**Appendix D17: EFA: CARRIS 17 Items: Treatment Participants: Eigenvalues and  
Percentage of Variance Explained**

Appendix D17

*EFA CARRIS: Treatment Participants: 17 Items, 62 Participants: Eigenvalues and Variance Explained*

Factor Number.	Eigenvalue	% of Variance Explained	Cumulative % of Variance Explained
1	5.620	33.060	33.060
2	2.606	15.330	48.390
3	1.692	9.952	58.343
4	1.230	7.233	65.576
5	1.147	6.746	72.322
6	.775	4.560	76.882
7	.698	4.107	80.989
8	.544	3.200	84.189
9	.541	3.182	87.372
10	.481	2.832	90.203
11	.381	2.239	92.443
12	.325	1.913	94.355
13	.303	1.784	96.139
14	.213	1.256	97.395
15	.195	1.148	98.543
16	.128	.755	99.298
17	.119	.702	100.000

## Appendix D18: EFA: CARRIS 17 Items: Treatment Participants: Pattern Matrix: 3

### Factor Solution

Appendix D18

*EFA CARRIS: Treatment Participants: 17 Items (variables), 62 Participants (cases): Pattern Matrix (loadings suppressed at <.32*

CARRIS Item	F1	F2	F3
(45) I feel anxious during sexual activity	.915		
(59) I feel anxious immediately prior to sexual activity	.889		
(69) I feel comfortable with my appearance in sexual situations	.752		
(33) I am able to relax and fully enjoy sexual activity	.648		
(52) I feel discomfort at being seen naked by a partner	.617		
(53) I would alter my sexual behaviour because of how I look	.552		
(24) I would avoid undressing in front of a partner	.512		
(70) A new partner would be put off me by my appearance		.975	
(35) Other people are repelled by my appearance	-.356	.818	
(62) I would be worried about telling a potential or new partner about my appearance		.684	
(56) I feel physically attractive		.594	
(29) My appearance is an extra barrier to me developing romantic relationships		.339	
(12) I would feel able to openly discuss my appearance with a partner			.764
(46) My partner could understand how I feel about my appearance			.625
(57) Speaking about how I look with a partner would be a positive experience			.592
(71) My partner would be able to provide me with support and comfort if I felt unhappy about how I look			.572

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Arranged by primary Factor and in order of descending loadings

Extraction Method: Principal Axis Factoring

Rotation Method: Promax

Rotation converged in 4 iterations

## Appendix E1: CFA: University Research Ethics Committee: Amendment to Existing Research Ethics Approval

*Please complete this form if you wish to make an alteration or amendment to a study that has already been scrutinised and approved by the Faculty Research Ethics Committee and forward it electronically to the Officer of FREC (researchethics@uwe.ac.uk)*

<b>UWE research ethics reference number:</b>	HAS.17.01.092
<b>Title of project:</b>	Questionnaire study to be conducted on-line / via paper copies related to visible difference and romantic intimate relationships
<b>Date of original approval:</b>	24/02/2017
<b>Researcher:</b>	Nick Sharratt
<b>Supervisor (if applicable)</b>	Professor Nichola Rumsey

**1. Proposed amendment:** Please outline the proposed amendment to the existing approved proposal.

The existing approval was in respect of the development of a measure of the impact of visible difference upon romantic intimate relationships. The data collected has been analyzed and a refined, shorter measure developed. In order to validate this measure, further data is required. The 17 items were all included in the original measure and the demographic details that will be supplied are very similar (with only minor alterations included for convenience).

**2. Reason for amendment.** Please state the reason for the proposed amendment.

As the work to date was required to be conducted before it was known which items would comprise the refined scale, it was not possible to include this in the original application and as this is a continuation of the project and uses items that have already been approved, requests demographic details that have previously been supplied and involves a smaller burden on participants, an amendment seems appropriate.

**3. Ethical issues.** Please outline any ethical issues that arise from the amendment that have not already addressed in the original ethical approval. Please also state how these will be addressed.

The revised scale is 17 items whereas the previous long-form version was 74. Participants will not, at this stage, be asked to complete other measures (as they previously were). The time commitment is thus greatly reduced and we anticipate participation taking under 10 minutes. In light of this we wish to offer participants the chance to enter a draw

for a £10 Amazon voucher rather than provide a thank you payment to every participant as we previously did. We have approximately 30 vouchers left so anticipate being able to provide a voucher for every 10 participants (at most).

We are not asking for participants to identify themselves but will ask that they provide a UK / Irish phone number and an email address so they can be contacted in respect of the vouchers and to verify that they are based in the UK / Ireland. We will also email willing participants approximately 4 weeks after participation so that they may complete the measure again (for test-retest reliability). As before, this data will be stored within Qualtrics and (when emails are sent) on the servers of UWE and in the researcher's UWE email account.

Revised documentation is supplied with this application and the Qualtrics site will mirror this documentation in all substantial and significant respects.

**To be completed by supervisor/ Lead researcher:**

**Signature:**

NR

**Date:**

01.12.17

**To be completed by Research Ethics Chair:**

**Send out for review:**

☐ Yes

x No

**Comments:**

These amendments do not raise any further ethical issues so can be approved

**Outcome:**

x Approve

☐ Approve subject to conditions

☐ Refer to Research Ethics Committee

**Date approved:**

1st December 2017

**Signature:**

Guidance on notifying UREC/FREC of an amendment.

Your study was approved based on the information provided at the time of application. If the study design changes significantly, for example a new population is to be recruited, a different method of recruitment is planned, new or different methods of data collection are planned then you need to inform the REC and explain what the ethical implications might be. Significant changes in participant information sheets, consent forms should be notified to the REC for review with an explanation of the need for changes. Any other significant changes to the protocol with ethical implications should be submitted as substantial amendments to the original application. If you are unsure about whether or not notification of an amendment is necessary please consult your departmental ethics lead or Chair of FREC.

## Appendix E2: CFA: Participant Information Sheet

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.

#### ***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 to understand the nature and extent of this impact.

We have therefore developed a measurement scale that focusses upon visible difference and intimate, romantic relationships. This has been created as a result of a series of interviews and reduced to a practical length after over 250 people completed a longer version of the scale. We now need to ask more people to complete the refined version in order to further validate it.

The results of the Study will be published to improve healthcare and research professionals’ understanding of the area and we hope to make the scale available for future use by researchers and healthcare professionals.

#### ***Why have I been chosen to participate?***

You are being asked to participate if you are at least eighteen years old, live or are based in the UK or Ireland, 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. In 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.

#### ***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 short questionnaire of 17 items relating to visible difference, intimacy, romantic relationships and sexual activity. We think that this should take about 10 minutes in total. You will also be

asked if you are prepared to complete the questionnaire again in approximately 4 weeks' time. If you agree to continue your participation in this way then this information sheet and the consent you provide shall also apply to your continued involvement.

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.

### ***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.

### ***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 questionnaire will be used in the future to help assess the impact of visible differences upon intimate relationships. Your participation will help us achieve these aims.

As a small thank you for taking part we are able to offer each participant that completes the study a chance to enter a draw for one of a number of £10 Amazon voucher codes. We anticipate being able to offer approximately one voucher for every 10 participants.

To be eligible for this you need to complete the questionnaire and provide a UK or Irish phone number and an 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.

Voucher codes cannot be provided if the questionnaires are not completed properly and attentively nor if you fail to provide a working UK or Irish phone number (land-line or mobile) on which you can be contacted and an email or postal address.

### ***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. 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 can be found at the web-pages of either: [Changing Faces](#) or [The Centre For Appearance Research](#) (both hyperlinked)

### ***Who is running and funding the research?***

The Study is funded by the University of the West of England ('UWE') and is being conducted by researchers in the Centre for Appearance Research at UWE. Details of the main researchers involved are provided below.

***Who has reviewed the Study?***

The Study has been reviewed and approved by an ethics committee from the Faculty of Health and Applied Sciences at UWE.

***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 (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 (see 10, below).

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 be entered into the draw (described below).

***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.

***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 to 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 be eligible to receive an Amazon voucher then you must provide an email address and UK or Irish phone number with which you can be contacted. This information will be subject to this Data Protection Notice and will be used by the researchers to contact you in the event that you are successful in the draw and/or to verify that the number you provide is a UK or Irish phone number.
- g) If you consent to complete the questionnaire again in approximately 4 weeks and provide an email address upon which you can be contacted then this information will be used by the researchers to send you further details and a request that you complete the questionnaire again. That information and any subsequent data you provide will be subject to this Data Protection Notice.

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

***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](mailto: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 Associate Professor Tim Moss who can be contacted by phone on 0117 32 82189. Associate Professor Moss is supervising the performance of the Study.

The address of the Centre for Appearance Research is:

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

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

## Appendix E3: CFA Consent Form

Centre for Appearance Research  
Faculty of Health and Applied Sciences  
University of the West of England  
Frenchay  
Bristol, BS16 1QY  
Tel: 0117 328 2497

### ***‘Visible Differences, Intimacy and Romantic Intimate Relationships’ (the ‘Study’)***

#### **PARTICIPANT CONSENT FORM AND DATA PROTECTION NOTICE**

**I confirm that:**

	Please tick or otherwise mark to indicate your consent
9. I am 18 years of age or over and live or am based in the UK or Ireland	<input type="checkbox"/>
10. I understand that I should not participate if I have a diagnosed mental health condition which is currently uncontrolled by medication or intervention and which has a significant impact upon the activities of daily living. I do not have such a condition	<input type="checkbox"/>
11. I have read the information sheet for the Study (version 1.1 dated 29/11/2017), I understand it and I have had the opportunity to contact the research team and ask them any questions that I have about it	<input type="checkbox"/>
12. I understand that taking part in this study will involve me completing a short questionnaire exploring my experiences and feelings related to visible difference, intimacy and sexual activity	<input type="checkbox"/>
13. I understand that I can chose not to answer any question I do not want to answer	<input type="checkbox"/>
14. I understand that I can withdraw my participation in the Study at any time and without providing any reason for doing so by ceasing to complete the questionnaire. If I do withdraw my participation in this way, I understand that any data I have already provided may be used unless I expressly withdraw it from the study during the period specified in this consent form	<input type="checkbox"/>
15. I understand that I may withdraw my data from the study but am only able to do so during the four week period immediately following the date upon which I provide that information. If I wish to withdraw my data I must contact the researcher and provide my participant code (generated below)	<input type="checkbox"/>

16.	I agree to the University of the West Of England processing my personal data as described in the Data Protection Notice within the information sheet for the Study (version 1.1 dated 29/11/2017)	<input type="checkbox"/>
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**I agree to all the above and I agree to participate in the Study:**

<input type="checkbox"/>	
<b>Please tick, cross or make any other mark to indicate your consent</b>	<b>Date</b>

In order for your data to be stored securely and so that we can identify it should you wish to withdraw from the study, we need to generate a code. Please provide:

<b>The first two letters of your first name (i.e. 'ni'):</b>	
<b>The day of the month on which you were born (i.e. '12'):</b>	
<b>The first two letters of the name of your first school (i.e. 'ru'):</b>	

If you would like to be entered into a draw for one of a number of £10 Amazon vouchers as a thank you for your proper and attentive participation then please provide a UK or Irish phone number (mobile or landline) and an email address so that you may be contacted in connection with your participation and/or to verify that the phone number you provide is a UK or Irish land or mobile phone number and/or so that a code can be sent to you if you are successful in the draw.

Please note that we are unable to provide an Amazon voucher (even if you are successful in the draw) if you do not provide a UK or Irish phone number on which you can be contacted.

<b>Email address</b>

<b>UK/Irish phone number</b>



## Appendix E4: CARRIS: 17 Items

### Centre for Appearance Research Romantic relationships and Intimacy Scale (CARRIS)

Please read the following statements and consider how strongly you agree or disagree with each of them.

If a question appears to not apply to you because of your current circumstances, for example, if it's about a new relationship but you are currently in a relationship or it mentions a partner but you are currently single, please imagine how you would feel if it was applicable. If it is not applicable to you for some other reason, please choose the 'not applicable' option.

Please read the questions carefully but don't spend too long on any one question.

#### Item

1. A new partner would be put off me by my appearance
2. I feel discomfort at being seen naked by a partner
3. I would feel able to openly discuss my appearance with a partner
4. I would alter my sexual behaviour because of how I look
5. I feel anxious during sexual activity
6. I feel physically attractive
7. My partner would be able to provide me with support and comfort if I felt unhappy about how I look
8. I would avoid undressing in front of a partner
9. Speaking about how I look with a partner would be a positive experience
10. I feel anxious immediately prior to sexual activity
11. A partner would feel little sexual desire for me
12. I feel comfortable with my appearance in sexual situations
13. Other people are repelled by my appearance
14. I am able to relax and fully enjoy sexual activity
15. I would be worried about telling a potential or new partner about my appearance
16. My partner could understand how I feel about my appearance
17. My appearance is an extra barrier to me developing romantic relationships

Response options

<i>Not Applicable</i>	<i>Strongly Disagree</i>	<i>Moderately Disagree</i>	<i>Slightly Disagree</i>	<i>Slightly Agree</i>	<i>Moderately Agree</i>	<i>Strongly Agree</i>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Appendix E5: CARRIS: 17 Items with Factor Structure and Reverse Scoring

### Centre for Appearance Research Romantic relationships and Intimacy Scale (CARRIS)

Please read the following statements and consider how strongly you agree or disagree with each of them.

If a question appears to not apply to you because of your current circumstances, for example, if it's about a new relationship but you are currently in a relationship or it mentions a partner but you are currently single, please imagine how you would feel if it was applicable. If it is not applicable to you for some other reason, please choose the 'not applicable' option.

Please read the questions carefully but don't spend too long on any one question.

Item	Factor	Reverse score
1. A new partner would be put off me by my appearance	2	
2. I feel discomfort at being seen naked by a partner	1	
3. I would feel able to openly discuss my appearance with a partner	3	x
4. I would alter my sexual behaviour because of how I look	1	
5. I feel anxious during sexual activity	1	
6. I feel physically attractive	2	x
7. My partner would be able to provide me with support and comfort if I felt unhappy about how I look	3	x
8. I would avoid undressing in front of a partner	1	
9. Speaking about how I look with a partner would be a positive experience	3	x
10. I feel anxious immediately prior to sexual activity	1	
11. A partner would feel little sexual desire for me	2	
12. I feel comfortable with my appearance in sexual situations	1	x
13. Other people are repelled by my appearance	2	
14. I am able to relax and fully enjoy sexual activity	1	x
15. I would be worried about telling a potential or new partner about my appearance	2	
16. My partner could understand how I feel about my appearance	3	x
17. My appearance is an extra barrier to me developing romantic relationships	2	

Response options

<i>Not Applicable</i> (0)	<i>Strongly</i> <i>Disagree</i> (1)	<i>Moderately</i> <i>Disagree</i> (2)	<i>Slightly</i> <i>Disagree</i> (3)	<i>Slightly</i> <i>Agree</i> (4)	<i>Moderately</i> <i>Agree</i> (5)	<i>Strongly</i> <i>Agree</i> (6)
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Scale authored by N.D. Sharratt, Dr T. Moss, Dr E. Jenkinson, Dr A. Clarke, Professor N. Rumsey.  
All the moral rights of the authors have been asserted



Higher score is indicative of greater appearance distress within the romantic context

Factor 1: Sexual Anxiety and Self Consciousness

Factor 2: Negative Evaluation and Being Judged as Unattractive

Factor 3: Benefiting from Partner Empathy

## Appendix E6: CFA: CARRIS 17 Items: Modification Indices

### Appendix E6

#### *CFA: CARRIS 17 Items: Modification Indices*

Covaried Item error i.	Covaried Item Error/Factor ii.	Modification Index*	Parameter Change**
Items loading upon the same factor as one another (covariance considered)			
Item 8 (Factor 1)	Item 2 (Factor 1)	26.531	.646
Item 14 (Factor 1)	Item 10 (Factor 1)	10.906	.479
Item 10 (Factor 1)	Item 5 (Factor 1)	9.660	.372
Item 14 (Factor 1)	Item 8 (Factor 1)	6.995	-.390
Item 15 (Factor 2)	Item 1 (Factor 2)	6.305	.325
Item 5 (factor 1)	Item 4 (Factor 1)	4.700	.268
Item 12 (factor 1)	Item 5 (Factor 1)	4.463	-.232
Item 14 (Factor 1)	Item 4 (Factor 1)	4.126	-.303
Items loading upon different factors to one another (covariance not considered)			
Item 8 (Factor 1)	Item 11 (Factor 2)	13.041	.500
Item 1 (Factor 2)	Item 7 (Factor 7)	9.499	-.334
Item 8 (factor 1)	Item 17 (Factor 2)	7.888	-.452
Item 10 (Factor 1)	Item 13 (Factor 2)	7.660	-.366
Item 14 (Factor 1)	Item 16 (Factor 3)	7.644	.475
Item 4 (Factor 1)	Item 15 (Factor 2)	6.883	.435
Item 4 (Factor 1)	Item 3 (Factor 3)	4.807	.311
Item 5 (Factor 1)	Item 7 (Factor 3)	4.387	-.280
Item 8 (Factor 1)	Item 3 (Factor 3)	.4179	-.286
Items and factors (covariance not considered)			
Item 11 (Factor 2)	Factor 1	15.075	.482
Item 11 (Factor 2)	Factor 2	10.059	-.208
Item 13 (Factor 2)	Factor 1	9.229	-.369
Item 1 (Factor 2)	Factor 3	7.638	-.203
Item 13 (Factor 2)	Factor 2	6.713	.168
Item 7 (Factor 3)	Factor 2	6.351	-.168
Item 14 (Factor 1)	Factor 3	6.263	.273
Item 10 (Factor 1)	Factor 2	4.859	-.133
Item 4 (Factor 1)	Factor 2	4.129	.126

\*Estimated reduction in  $\chi^2$  if parameter freed (errors permitted to covary)

\*\*Estimated change in covariance between specified items / factors

## Appendix E7: CFA: CARRIS 16 Items: Modification Indices

### Appendix E7

#### CFA: CARRIS 16 Items: Modification Indices

Covariied Item error i.	Covariied Item Error/Factor ii.	Modification Index*	Parameter Change**
Items loading upon the same factor as one another (covariance considered)			
Item 14 (Factor 1)	Item 4 (Factor 1)	8.429	-.421
Item 14 (Factor 1)	Item 10 (Factor 1)	6.568	.354
Item 15 (Factor 2)	Item 1 (Factor 2)	6.247	.324
Item 12 (Factor 1)	Item 5 (Factor 1)	5.992	-.269
Item 10 (Factor 1)	Item 5 (Factor 1)	4.384	.236
Items loading upon different factors to one another (covariance not considered)			
Item 1 (Factor 2)	Item 7 (Factor 3)	9.156	-.328
Item 14 (Factor 1)	Item 16 (Factor 3)	8.532	.491
Item 10 (Factor 1)	Item 13 (Factor 2)	8.006	-.365
Item 4 (Factor 1)	Item 15 (Factor 2)	7.256	.444
Item 12 (Factor 1)	Item 11 (Factor 2)	4.375	.275
Items and factors (covariance not considered)			
Item 11 (Factor 2)	Factor 1	11.431	.449
Item 13 (Factor 2)	Factor 1	9.569	-.396
Item 1 (Factor 2)	Factor 3	7.758	-2.19
Item 11 (Factor 2)	Factor 2	7.542	-.186
Item 14 (Factor 1)	Factor 3	7.087	.304
Item 13 (Factor 2)	Factor 2	6.661	.170
Item 10 (Factor 1)	Factor 2	6.601	-.153
Item 7 (Factor 3)	Factor 2	5.532	-.159
Item 10 (Factor 1)	Factor 1	4.200	.233
Item 4 (Factor 1)	Factor 2	4.130	.127

\*Estimated reduction in  $\chi^2$  if parameter freed (errors permitted to covary)

\*\*Estimated change in covariance between specified items / factors

### Appendix E8: CFA: CARRIS 16 Items: Standardised Residuals Covariance Matrix

Appendix E8

*CARRIS: CFA: 16 Items: Standardised Residuals Covariance Matrix*

	Item 3	Item 7	Item 9	Item 16	Item 1	Item 6	Item 11	Item 13	Item 15	Item 17	Item 2	Item 4	Item 5	Item 10	Item 12	Item 14
Item 3	.000															
Item 7	.349	.000														
Item 9	-.077	-.203	.000													
Item 16	-.787	.767	-.045	.000												
Item 1	-.031	-2.814	-.805	-1.077	.000											
Item 6	.690	-.326	1.066	.472	.073	.000										
Item 11	.066	.250	.727	-.808	-.571	-.150	.000									
Item 13	.189	-1.406	.137	.403	.584	.467	-.214	.000								
Item 15	.867	-.892	-.023	.254	1.341	-.374	-.697	.352	.000							
Item 17	.612	-1.333	-.557	.915	.587	-.119	-.769	.974	.271	.000						
Item 2	.713	.613	.307	-.498	.133	.460	1.383	-.756	.189	-.378	.000					
Item 4	1.503	-.779	-.049	-.774	.575	.279	1.587	-.886	1.504	-.208	-.111	.000				
Item 5	.595	-1.329	-.651	-1.167	-.558	-.822	.377	-1.122	-.300	.260	.001	.387	.000			
Item 10	.152	.099	-.713	-.530	-.685	-.813	.751	-2.496	-.845	-.393	-.278	-.249	.467	.000		
Item 12	.255	.603	.223	-.120	-.230	.609	1.923	-.467	.202	.167	.303	.109	-.573	-.046	.000	
Item 14	1.020	1.514	.360	1.936	.228	.075	.422	-1.454	-.449	.315	-.360	-1.067	.244	.801	-.075	.000

## Appendix E9: CFA: CARRIS 16 Items: Regression Weights and Factor Correlations

### Appendix E9.i

#### CFA: CARRIS 16 Items: Unstandardized and Standardised Regression Weights

Item	Factor	Unstandardised		Standardised		<i>p</i> value*
		Regression Weight	Regression Weight	Standard Error	Critical Ratio*	
Item 14	F1	.695	.844	.093	9.078	<.001
Item 12	F1	.808	.932	.084	11.131	<.001
Item 10	F1	.823	1.000	-	-	-
Item 5	F1	.826	1.003	.087	11.499	<.001
Item 4	F1	.769	.898	.086	10.389	<.001
Item 2	F1	.763	.952	.093	10.287	<.001
Item 17	F2	.514	1.130	.207	5.466	<.001
Item 15	F2	.568	1.318	.221	5.971	<.001
Item 13	F2	.515	.948	.173	5.470	<.001
Item 6	F2	.841	1.394	.170	8.177	<.001
Item 1	F2	.658	1.000	-	-	-
Item 16	F2	.576	1.049	.225	4.671	<.001
Item 9	F3	.641	1.137	.231	4.914	<.001
Item 7	F3	.585	1.000	-	-	-
Item 3	F3	.544	.937	.207	4.514	<.001
Item 11	F3	.684	1.495	.213	7.009	<.001

\*critical ratio = parameter estimate divided by its standard error. These are similar to *z* values. A value >2 indicates the estimate is significantly different from 0 at the .05 level. The *p* value provides tests the significance of the pathway. As the regression weights show are concerned with pathways between items and the factors onto which they load, this should be significant and critical values should be >2.0.

### Appendix E9.ii

#### CFA: CARRIS 16 Items: Estimated Factor Correlations

	Factor 1	Factor 2	Factor 3
Factor 1	-	.79	.43
Factor 2	.79	-	.57
Factor 3	.43	.57	-

This is a pre-publication version of the following article:

Sharratt, N. D., Jenkinson, E., Moss, T., Clarke, A., & Rumsey, N. (2018). Understandings and experiences of visible difference and romantic relationships: A qualitative exploration. *Body image*, 27, 32-42. <https://doi.org/10.1016/j.bodyim.2018.08.002>

**Understandings and experiences of visible difference and romantic relationships: A qualitative exploration**

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**Declaration of Competing Interests**

Declarations of interest: none

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## **Abstract**

The association between disfigurement ('visible difference') and romantic relationships has received relatively little consideration in the research literature. This qualitative research, conducted in the United Kingdom, explored participants' accounts of their visible difference and romantic life. Semi-structured interviews were conducted with 22 participants who had a variety of visible differences. Inductive thematic analysis demonstrated that participants understood their difference as having a pervasive and enduring impact. These encompassed challenges that must be negotiated in the formation of romantic relationships, including feeling unattractive to others and feeling personally devalued. Relevant physical and sexual sequelae were comprised of anxieties regarding informing partners of a difference, impacted sexual activity, and concerns about heritability. Finally, the potential for partner support and acceptance to positively impact romantic relationships was recognised. This research highlighted the need to extend our understanding of visible difference and intimate relationships and to develop effective interventions to ameliorate appearance-related concern.

**Keywords:** Visible difference; Disfigurement; Romantic relationships; Intimacy

## Introduction

The study of body image and sexuality has featured in the research literature, with much of this work devoted to the association between negative body image and sexual function in women (Woertman & van den Brink, 2012). This association includes lower sexual desire (Koch, Mansfield, Thureau, & Carey (2005), arousal (Sanchez & Kiefer, 2007), satisfaction (Calogero & Thompson, 2009), sexual esteem and sexual assertiveness, as well as higher sexual anxiety and sexual problems (Weaver & Byers, 2006) and increased sexual avoidance (La Rocque & Cioe, 2011) in those with negative body image. These relationships have been linked with cognitive self-absorption, which is an intense fixation upon, and monitoring of, an individual's own bodily parts or *spectatoring* (Masters & Johnson, 1970) during sexual activity (Woertman & van den Brink, 2012). Similarly, Woertman and van den Brink (2012) proposed that the application of the model of sexual functioning proposed by Barlow (1986) posits that anxious self-evaluation and self-focus during sexual activity may cause cognitive distraction and adversely impact sexual function.

The contention that negative body image contributes to cognitive distraction during sex is consistent with the findings of Meana and Nunnink (2006) who demonstrated that negative body image predicted appearance-based sexual distraction in both college men and college women. Measures of sexually contextualised body image, including self-focus, self-consciousness, and avoidance of bodily exposure during sexual activity, have been shown to better predict disrupted sexual functioning than general measures of body image (Cash, Maikkula, & Yamamiya, 2004; Woertman & van den Brink, 2012; Yamamiya, Cash, & Thompson, 2006) and to mediate the association between body image and sexual functioning (Sanchez & Keifer, 2007).

Conversely the literature also indicates that positive body image may contribute to increased sexual desire and improved sexual function. This has been found in studies that have shown a positive association between body esteem and sexual desire (Seal, Bradford, & Meston, 2009) and between body appreciation and sexual function (Satinsky, Reece, Dennis, Sanders, & Bardzell, 2012). Furthermore, Swami, Weis, Barron, and Furnham (2017) suggested that positive body image may protect the individual from spectatoring and therefore permit greater sexual liberalism and more positive attitudes to unconventional sexual practices.

### **Visible Difference**

Whilst the research discussed so far has centred upon body image and sexuality, it is also apparent that those with appearance-altering conditions or an altered appearance may believe their sexual and romantic lives to have been impacted by their appearance. Such differences in appearance may be understood as constituting “visible difference” and have been defined by Kent and Thompson (2002, p.103) as “potentially noticeable differences in appearance that are not culturally sanctioned.” These authors also assert that visible difference may result from congenital conditions, traumatic events, disease processes, and medical treatment.

The challenges to psychosocial well-being that visible difference can present have been summarised by Rumsey and Harcourt (2004). These included challenges identified in academic commentaries discussing social and cultural adversities, such as discrimination, the negative judgements and reactions of others (Kent & Thompson, 2002), and stigmatisation (Goffman, 2000; Kent, 2000). Furthermore, they encompassed individual, psychological difficulties including low self-esteem, high levels of anxiety, depression, social anxiety, social avoidance, and reduced quality of life, as indicated by mixed-methods empirical research (Rumsey, Clarke, &

Musa, 2002; Rumsey, Clarke, & White, 2003) and via the review of Thompson and Kent (2001). Individual adjustment and appearance anxiety is, however, not well predicted by the nature of the difference nor linearly related to or predicted by objective measures of size or severity, as demonstrated empirically by Moss (2005), Ong and colleagues (2007), Rumsey and colleagues (2003), and Rumsey, Clarke, White, Wyn-Williams, and Garlick (2004).

It is, however, important to acknowledge that many individuals with a visible difference do not report psychosocial difficulties and that qualitative analyses have explored the possibility of visible difference exerting a positive influence upon the lives of those affected. Eiserman (2001) interviewed 11 adults with craniofacial conditions about their experiences of living with a visible difference. The themes identified captured how those living with craniofacial difference attributed a sense of meaning and coherence in life to looking different, as well as a plethora of positive attributes, such as enhanced communication skills, inner strength, and a valuable social circle to the presence of their difference. Egan, Harcourt, and Rumsey (2011) conducted individual and group interviews with adults with a range of visible differences who identified as adapting positively to their condition. Participants considered their visible differences to have facilitated personal growth by developing their resilience, resourcefulness, and calmness, and to have improved their relationships with, and understanding of, others. The consideration, support, and acceptance of partners was identified as being especially valuable in this respect and provided an indication of the importance of the intersection of romantic relationships and visible difference.

### **Visible Difference and Romantic Relationships**

Whilst adjustment to visible difference has received attention in the research literature, the specific sphere of visible difference and romantic relationships has

remained on the periphery of this body of work. Quantitative research has indicated that adult attendees of a plastic surgery outpatient clinic considered their intimate behaviours to be greatly affected by their appearance (Appearance Research Collaboration, 2014). Similarly, studies of those with a specific appearance-altering condition consistently report an impact upon sexuality and romantic relationships.

Porter and colleagues (1990) reported that 25% percent of 158 participants with vitiligo believed their condition to have impacted negatively upon their sexual relationships. In a larger study of 936 patients with psoriasis, between 35.5% and 71.3% of participants reported encountering sexual difficulties as a result of their psoriasis (Sampogna, Gisondi, Tabolli, & Abeni, 2007). The authors attributed the wide range in responses to the nature of the items to which participants were required to respond. Items that were more specific in nature and restricted to defined periods of time, such as the last week or the last four weeks, were endorsed so as to indicate lower levels of sexual difficulty than those which were more general and were not restricted in this way. Amongst those that had received treatment for head and neck cancer, one-third of respondents reported substantial problems with sexual interest and enjoyment, and one-quarter problems with intimacy (Low et al., 2009). Longitudinal research with patients with burn injuries indicated that burn injuries negatively impacted sexuality, body image, and relationship aspects of quality of life and that this effect subsisted regardless of good physical and functional recovery (Connell, Coates, & Wood, 2013; Connell, Phillips, Coates, Doherty-Poirier, & Wood, 2014)

Despite these quantitative studies indicating that visible difference may impact upon romantic and sexual life, there exists a paucity of qualitative research elucidating experiences and understandings of visible difference and romantic relationships and exploring the nature of these reported impacts. That which does

exist has focussed upon the experiences of adolescents. The qualitative data provided by adolescent participants in the work of Griffiths, Williamson, and Rumsey (2012) demonstrated that they believed appearance to be important in securing a relationship but felt unattractive, feared negative evaluation, found it difficult to talk with the other sex, attempted to conceal their difference, and feared revealing it to a new partner. Similar cognitions and behaviours were identified in an online qualitative study of eight adolescents with psoriasis, who reported avoiding intimate behaviours as a result of reduced self-confidence (Fox, Rumsey, & Morris, 2007), but explorations of this subject matter in adult populations have yet to be reported.

Whilst no previous qualitative research has specifically examined romantic relationships and visible difference amongst an adult population, qualitative research concentrated upon a particular condition or group of conditions has been reported. This has focussed upon those living with a broad range of appearance-altering conditions including below-the-knee amputations (Mathias & Harcourt, 2014), alterations in appearance associated with breast cancer (Ginter & Braun, 2017; Loaring, Larkin, Shaw, & Flowers, 2015), burn injuries (Connell, Coates, & Wood, 2015), psoriasis, acne, and eczema (Magin, Heading, Adams, & Pond, 2010), lymphedema (Winch et al., 2015, 2016), testicular cancer (Carpentier, Fortenberry, Ott, Brames, & Einhorn, 2011), and vitiligo (Thompson, Clarke, Newell, Gawkrödger, & The Appearance Research Collaboration, 2010). Participants in these studies experienced low self-confidence, low self-esteem, self-doubt, emotional and relational concerns, and internal fears of being judged, negatively evaluated, and rejected. Similarly, participants reported having experienced sexual difficulties, feelings of being physically unattractive, and being unable to meet a new partner. To the knowledge of the authors there exists, however, no previous reported research

dedicated to exploring experiences of visible difference and intimate, romantic relationships. It is this deficit that the current research sought to address.

In light of quantitative research demonstrating that visible difference and appearance-altering conditions may impact negatively upon sexuality and romantic relationships, the confirmation from a disparate body of qualitative work that this may be so, and the absence of qualitative research specifically dedicated to understanding and exploring the impact of visible difference upon romantic relationships in adults, the current research aimed to address the following research question: do participants with a visible difference understand their appearance to have impacted upon their intimate, romantic relationships? In order to then elucidate any such impact a second research question was adopted: how do participants with a visible difference understand, and how have they experienced, their appearance as impacting upon their intimate, romantic relationships?

## **Method**

### **Participants**

Semi-structured interviews were conducted with 22 participants living in the United Kingdom who were over the age of 18 years and who considered themselves to have a visible difference. This included 16 women and six men. Participants were aged between 25 and 64 with an average age of 43 years. Sixteen participants were married or in a relationship whilst six were single. All participants expressed heterosexual romantic preferences and spoke exclusively of heterosexual romantic experiences.

When considering the visibility of their difference in daily life, 12 participants stated that their difference was ordinarily visible to others and 10 believed their difference was not visible in this way. Eight participants had a condition they

described as congenital or genetic, whilst the remaining 14 had acquired their difference through injury, illness, or disease. The participants' visible differences were: alopecia (five participants), ankylosing spondylitis (one), breast cancer-related scarring (two), cleft lip and/or palate ('cleft') (six), facial birthmark (one), facial palsy (one), facial palsy and breast cancer-related scarring (one), facial scarring (one), ichthyosis (one), and psoriasis (three).

## **Materials**

In addition to audio-recording equipment and computer hardware and software (including Nvivo 11), an interview guide was developed for use in this research. The first author drew upon the existing literature to devise draft questions that were reviewed and revised with input from each of the co-authors, who drew upon their extensive research and clinical experience. These were reviewed by and pre-tested with other researchers in the research centre in which the first author is based but were not pilot tested with potential participants as they were to be deployed flexibly, in a responsive manner. There also existed a desire not to lose data and potential participants to the study as concerns relating to the number of participants that may volunteer to discuss this sensitive subject persisted. The questions that related to romantic relationships are included in Table 1. These questions were utilised flexibly within the context of each interview and follow-up questions were asked in response to each participant's account in order to afford primacy to their voice.

## **Procedures**

Semi-structured interviews were employed to explore participants' understandings and experiences of visible difference and romantic relationships, giving them freedom to express themselves whilst retaining a focus on the object of

the research. In an attempt to empower participants (Trier-Bieniek, 2012) and in recognition of the possibility that those taking part may have been anxious about meeting with, and being visually scrutinised by, a researcher, each participant was offered a choice between three forms of synchronous verbal communication. These were an interview conducted in person, over the telephone, or via an internet-mediated video service (Skype).

Having obtained ethical approval for this research from the University of the West of England faculty research ethics committee, the study was advertised by a university press release, on the social media accounts of the authors' research centre, and by 17 support groups and charitable organisations for those affected by visible difference. These organisations used a variety of methods, including social media, websites, and newsletters, in order to make their members and subscribers aware of the research. Potential participants contacted the researcher in response to these adverts. The researcher answered any questions they had, ensured they had access to full information about the study, and made practical arrangements for conducting the interviews. Each participant provided verbal or written fully informed consent before their interview was conducted. The first author conducted all the interviews. The first author had conducted qualitative focus groups and interviews (including interviews with staff and patients of the United Kingdom's National Health Service) in two previous research projects, had attended training sessions and benefited from the informal advice and guidance of supervisors and colleagues at three universities (including the one at which this research was conducted), and had extensive experience of providing a confidential listening and emotional support service to those in distress. The research team therefore considered the first researcher competent and prepared for this task. In support of this assessment and to help ensure the quality of the data, the first and last authors conducted regular debriefing sessions

in which the content of each interview and the first author's experience of conducting it were discussed and reflected upon.

Of the 22 participants, 15 chose to be interviewed over the telephone, five face-to-face, and two via Skype. The interviews lasted for an average of 65 minutes. The number of participants interviewed accords with guidance given by Braun and Clarke (2013, p. 48) that 20 interviews constitute a large sample for interview studies employing thematic analysis. Recruitment ceased when data saturation was adjudged to have occurred. This was assessed on the basis of the ongoing review and analysis of interview notes, reflection on the data, and when the generation of emerging codes indicated that the data were comprehensive in scope, rich in nature, and the accounts of multiple participants demonstrated common essential characteristics (Morse, 1995, 2015). Participants were not offered and did not receive any remuneration or compensation in connection with their participation in this study. In order to protect participants' anonymity, pseudonyms have been used in this report.

### **Data Analysis**

The interview data were audio recorded and transcribed verbatim by an independent party before being thoroughly checked at least twice by the first author on a word-for-word basis for errors and misinterpretation of the dialogue. This confirmed the accuracy of the transcripts as well as ensuring the first author was thoroughly immersed in and familiar with the data, having also conducted all 22 interviews.

This familiarisation with the data constituted the first phase of the inductive approach to thematic analysis advocated by Braun and Clarke (2006, 2012, 2013) for exploratory studies. The inductive, data driven analysis gave priority to the accounts

of the participants and explored semantic features of the data in addition to its latent meanings.

The first author manually coded hardcopies of the entire data-set, deriving codes that described interesting features of the data. Example codes are provided in Table 2. The codes were collated and clustered into candidate themes and sub-themes. In line with the guidance of Braun and Clarke (2006), and as is consistent with the methodological approach adopted (Braun & Clarke, 2013, p.279, 2014; Terry & Braun, 2016), this process of coding the data was performed by the first author rather than by multiple, independent coders.

Throughout this process, however, the first author worked closely with the last author, a professor of appearance psychology with over 20 years' experience of conducting, collaborating in and supervising qualitative research. The first and last author met regularly to discuss coding, candidate themes, and candidate sub-themes. Such discussion included reference and referral to the transcribed interviews in order to ensure the analysis remained grounded in, and justified by, the data and was therefore credible, meaning that it was trustworthy, verisimilar, and plausible (Tracy, 2010). Decisions relating to the content and organisation of themes and sub-themes were taken jointly by the first and last author. The analysis was further reviewed, refined, and confirmed in two meetings between the first author, the second author, a senior lecturer in health psychology, and the third author, an associate professor in appearance psychology. The second and the third author each have over 10 years' experience of relevant qualitative research. A further review of the analysis was conducted separately in one meeting between the first author and fourth author, an experienced research active clinical psychologist. Furthermore, the second author independently coded one transcript and discussions between the first and second

author revealed a strong consensus with all pertinent issues and potential codes identified by the second author forming part of the analysis.

As part of this review process and in order to maintain an accessible record of the data, the first researcher utilised the Nvivo 11 software, coding the data set at the level of themes and sub-themes within this programme. The review process resulted in five candidate themes connected to romantic relationships and intimacy being collapsed into the three detailed below. “The Disclosure Dilemma” had been a candidate theme but was subsumed into “Looking Different: Physicality and Physical Reality” as a sub-theme. Components of a fifth candidate theme focussing upon the impact of appearance upon participants’ romantic identity were distributed amongst the final three. These are defined in the Results section below. In order to further ensure the credibility of the analysis (Tracy, 2010), a provisional summary of the findings was sent to the 21 participants that indicated they wished to receive this document. Five participants responded. All comments supported the analysis.

## **Results**

A total of five themes arose from the final analysis. Two themes were principally concerned with the participants’ thoughts, feelings, and experiences of visible difference in their daily life, whilst three related specifically to their intimate and romantic lives. In line with the focus of this paper, the three themes focussing on intimacy and romantic relationships are presented in Table 2 and presented within this report. This table also illustrates the organisation of these themes, their subthemes, and provides some example codes.

### **Appearance Attracts and Detracts**

This theme reflected participants' understanding that appearance is of fundamental importance to attraction and attractiveness to others and also that participants considered themselves to be personally devalued by their difference.

**Appearances are central to attraction.** This sub-theme was discussed by 19 of the 22 participants who, in espousing the centrality of appearance to attraction, suggested that a positive appraisal of their physical appearance and being perceived as being physically attractive was important to the formation of romantic relationships. The presence of a visible difference was characterised as negating the attractiveness of participants to others and was thus represented as an obstacle to potential relationships of this type:

You get somebody that's saying all the right things: "It doesn't matter" and "bloody hell, I'm going bald anyway" and then, to totally ignore you. Don't tell me it's not an issue when it obviously is. But I do understand because, honestly, and I'm not just saying it for you, I do understand. I do understand because we do, as much as you like to say "I love the person inside," it's a physical attraction that first makes you go over to that person and talk to them. It's a physical attraction that will make me or any man on a dating website scroll through pictures and go "Oh God, no, no, next one! Oh he's a bit of alright" You know? It's, that's what we do. It's what we do, isn't it? So I do understand and I try, I try really hard not to let it bother me. (Michelle, alopecia)

In some cases this was presented as the greatest challenge associated with visible difference:

The worst period for me was during the periods when I was a young person and wanted to be courting or should have been courting. That was the very worst period. And, again, perhaps I was out of the people insulting me time but I was

then into the period of how do I make myself presentable to the opposite sex?

(David, cleft)

Attractiveness was considered to be contextualised and dictated by societal appearance ideals, ideals to which visible difference did not conform:

I think a lot of it's the media and magazines and television as to what in Western society is deemed as attractive, whereas if you were in Hawaii or somewhere it might be big is beautiful or whatever, or Africa a long neck or whatever but, yeah, I think in Britain it's, or Western society it's, yeah, certain things are deemed to be more attractive than others and hair, particularly as a woman, is I suppose the crowning glory or the, I mean, it's just a sign of, of desirability, attractiveness, fitness, the whole shebang really. Youth. So I suppose, yeah, losing my hair I felt old or unattractive, yes. (Elaine, alopecia)

Appearance ideals and the importance assigned to judgements of attractiveness were believed to be applied more rigorously and felt more acutely by women than by men. Half the participants explicitly discussed the idea that women are subjected to relatively more appearance pressure, or were more liable to be assessed on the basis of how they look, than men:

My husband's got no hair, it's never really bothered him, I don't think. I don't know, perhaps I'm wrong but I do feel that women do seem to have more pressure on them. But then you hear a lot, don't you, of guys now having anorexia and dysmorphic and all that stuff so, yeah, maybe. Maybe I'm wrong about that but it does seem more of a female thing." (Karen, breast cancer)

In light of the perceived negative reactions and judgements of others, participants occasionally communicated concerns about whether another person could ever find them attractive. Such feelings were particularly pertinent to those who were

single at the time of the interview. The sense of diminished attractiveness to others was described by several participants and characterised as limiting their romantic opportunities. These participants believed that their difference made them a less attractive proposition as a partner and dictated that they could enter into a new romantic relationship only with an existing friend or someone with whom they had already developed a sense of trust and understanding:

It would be a lot harder to meet someone, to spend time with them in the first place, it would have to be either a friend-of-a-friend or someone that for some reason you've got to spend a bit of time with someone at work or something like that. (Ryan, facial palsy)

Despite the perceived disadvantages associated with appearance-based judgements, there was acknowledgment from seven participants that these judgements were natural, involuntary, and that they themselves may also evaluate others on a similar basis:

I'm probably the world's worst for judging people on looks as well. I look at people and think "Oh, I don't want to look like that!" You know you do, you know, I look at people who are bigger than me and think "Oh if I stop going on my bike I'm going to be that big" so I think it's kind of programmed into you. (Beth, facial scarring)

Finally, it is important to acknowledge that the accounts of three participants were not consistent with these ideas and indicated that their difference had not impacted their romantic lives, nor diminished their romantic prospects. Speaking about an ex-boyfriend who had told Vanessa he did not remember her psoriasis, Vanessa said:

He said ‘Some guys don’t even care about that as long as they can get the girl.

So, psoriasis really? Who cares?’ And apparently, he’s right. (Vanessa, psoriasis)

**The discounted self.** Whilst the previous sub-theme addressed concerns about how visible difference diminishes attractiveness to others, this second sub-theme addressed feelings of personal deficiency expressed by 19 of the 22 participants. These respondents deemed themselves to be devalued by their appearance, making them a less viable romantic partner:

I’ve got this one breast, if you like, and the other one was done but it’s an implant but there’s no nipple there, it’s like I’m deformed and there’s lots of scars... and I think it looks ugly... in my eyes already I’ve finished myself off because I think intimacy is out of the question now. (Valerie, facial palsy and breast cancer)

Such concerns were especially salient in the accounts of participants who were single at the time of their interview and for those in relationships when contemplating being single. Participants described adopting compensatory strategies as they sought to promote other socially- and culturally-desirable characteristics, which were more directly within their control. These included the sculpting of the body through physical exercise:

I couldn’t control my face but I could control myself from the shoulders down. So I did what I could with that and I still do with that. (Luke, cleft)

Participants thus conceptualised relationship formation as being akin to a negotiated exchange in which the relative worth of each partner is scrutinised by the parties involved. Deficiencies in appearance may be compensated for by other desirable characteristics, abilities, or status. Other qualities that were expressly

mentioned included cultivating a gregarious personality, obtaining a good education, job status, wealth, and possessing the currency of relative youth:

I've always thought that I'm not good enough sometimes, you know, why would someone good looking want to be with me? And then so, in that respect I've gone for older men who haven't been as youthful. Then, when I was 27, I ended up with a 44-year-old and he just turned out to be the biggest idiot ever. But I kind of latched onto him because I was thinking "It's safer. He's not going to leave me" and "He should be grateful he's with someone so young, you know, regardless of what I look like, you know." (Beth, facial scarring)

Ten of the participants who were either enjoying or could envision a healthy relationship attributed this situation to luck, good fortune, or the rarefied and special qualities of their partners who accepted them despite their difference. An additional participant speculated that other people with a visible difference may feel this way but did not personally subscribe to this notion. In several instances, this combination of feeling devalued but also lucky or grateful had contributed to a tendency to accept unrewarding relationships. Three participants maintained that they got married to someone precisely because of such feelings:

I ended up marrying the wrong person... he, you know, was being a moral support and I thought uhm, no-one else will ever want me again, no-one else will ever find me attractive, he wants me, I'd best just settle for this then, you know? So I think in hindsight if I hadn't have lost my hair, I would never have settled with him and, you know, got married. (Elaine, alopecia)

### **Looking Different: Physicality and Physical Reality**

This second theme is devoted to the physical consequences of living with a visible difference and how these impact upon romantic relationships.

**The disclosure dilemma.** This sub-theme was discussed by 13 participants. This included 9 of the 10 participants who considered that their difference was not immediately visible or was ordinarily concealed. In addition, this theme included contributions from participants who said that the visibility of their condition fluctuated, from those whose difference could be concealed but who routinely chose not to hide it, and from one participant with multiple differences (some normally visible, some not).

For these participants, the moment of disclosure of their difference assumed central importance in their experiences of visible difference and romantic life. Those in established relationships could recall the concern they had felt as this moment approached, whilst for single participants the anxiety was ongoing. This moment of disclosure represented an extra hurdle to overcome in forming a relationship. One participant considered this insurmountable:

I've got to explain, well actually, you know, I'm deformed as well on the chest. I couldn't see myself right now or the near future explaining that to anybody because at least I can hide that. At least no-one can see that but me. (Valerie, facial palsy and breast cancer)

Elaine explained why this revelation of a physical difference was so problematic:

I'm presenting one image to the world but the reality is something else, so they've got to then get their head around the fact that I'm not this woman with long hair and whatever and I'm actually bald. So they meet one woman but if they go to bed with me it's a totally different woman and they think "Oh, who's this?" (Elaine, alopecia)

As alluded to by Valerie and Elaine, physical intimacy was viewed as the defining point before which this disclosure was required. Contributing participants

were unanimous in considering it necessary to tell a partner about their difference rather than have them discover it. This approach was related to a conviction that if they were to avoid telling a new partner about their difference this would be interpreted by the partner as being deceitful, deceptive, or dishonest. Yet, despite the conviction that telling a partner was of great importance, the act itself was characterised by uncertainty and anxiety regarding how, where, and when to do so and how that other person would react. Speaking about Internet dating sites, Michelle said:

(I) had various different thoughts off people as to what I should do with regards to my alopecia, from “No, make sure all your photos on there you have got wigs on,” “You shouldn’t have to tell anybody anything about it,” “Let them get to know you as a person first.” But then I feel I’m being quite deceitful in that regard so, after lots of trials we have now settled on my page with photos of me with wigs and a couple of daft ones of me polishing my head with a can of Brasso [laughs]. (Michelle, alopecia)

The pictures were then integrated into a deliberate disclosure strategy in an attempt to overcome this uncertainty and anxiety. Michelle described how she would turn the conversation to these photos which could be (and had been) mistaken for pictures of her engaging in charity fundraising activity. Other participants spoke about strategies used to minimise the chances of a hurtful response, such as disclosing at the end of a date, doing so on neutral territory, and disclosing remotely by messaging or phoning potential dates before meeting. Such strategies did not guarantee positive reactions but helped participants exert control over the disclosure scenario and to some extent, limited their exposure to hurtful responses. The discomfort associated with uncertainty about the nature of the reactions of others appeared to drive participants’

anxiety. This was reflected in descriptions of the variety of reactions experienced in the past, ranging from palpable shock and rejection to acceptance and understanding:

With my current boyfriend, again, I would, I always feel a bit nervous. I remember showing him and him just saying he liked it so, it was very positive.  
(Chloe, facial birthmark)

**Invading physical intimacy.** This sub-theme conveys the impact of their visible difference upon physical intimacy and sex and was drawn from the accounts of 17 of the 22 participants. These participants described three discrete effects. The first was a reduction in the desire for sexual contact, attributed to feeling deeply unattractive. For participants who did not have a partner this could manifest itself through the avoidance of situations that may lead to sex:

When I've got it at its height, it still does rather worry me. It almost makes it as if there's a sort of a "hunting season," although, not the word I want "mating season" as it were, outside of the time when my condition has got particularly bad. I know it's a bit pathetic and all the rest of it, especially knowing what I know objectively but, yes, I do think it will have an effect on my confidence in that respect. (Austin, psoriasis)

Some participants in relationships rejected the advances of their partner because of such feelings. This represented a physical manifestation of participants' anxiety about their attractiveness to others and their low physical or sexual self-esteem. Some female participants whose difference affected feminised and sexualised areas of the body ascribed this to a reduced sense of femininity:

Our sex life has been completely interrupted during all this... and I kind of know when we're going to do it because I leave a bra on... (it has) just has taken away every idea of femininity completely... you're just like an alien. No eyebrows, no

eyelashes, nails, things that kind of you see as feminine, lovely long painted nails, lovely mascara eyelashes. (Jodie, breast cancer)

The second, less pervasive effect was that some participants felt discomfiture at being seen naked by their partner and would conceal their difference during physically intimate moments. Jodie's extract has already illustrated this "shrouding." In describing the use of towels and wraps to cover up and how it felt to be seen naked by her loving and supportive partner, Sian alludes to the powerful way in which this could diminish intimacy within a relationship:

(I) feel like I could be standing naked in front of a stranger, or a stranger walks in the room when I'm naked. (Sian, ankylosing spondylitis)

The final component of this sub-theme refers to the perceived tendency of visible difference to detract from participants' ability to enjoy sexual contact with a partner. Visible difference was therefore understood as having the ability to 'steal the moment:'

It just stops you being in the moment, I guess sometimes. If you're moving your head on the pillow and you then remember you haven't got any hair. (Florence, alopecia)

This was not necessarily the result of a partner noticing the difference or behaving in a way that made participants feel uneasy. Charlotte explained that during sex she felt compelled to alter position to make her difference less visible, even though she acknowledged that this was more of an issue for her than for her partner:

He's not looking at it, or my ex-boyfriend wasn't looking, obviously busy doing what else, but... for some reason it will pop in and I'll be like "Ah... I've got... I don't want. Um..." I've got to move because I don't want him to look at me. (Charlotte, cleft)

**Concerns over the heritability of appearance-altering conditions.** Nine participants with conditions that may include a genetic component, including all six participants with cleft, two with dermatological conditions, and the participant with ankylosing spondylitis, contributed to this sub-theme. They spoke about the possibility of their children acquiring the condition and the impact this may have upon their child's life:

If it was a girl I, well, like I said, if, I would've been really, really heartbroken.

Not for me but for them and the impact it would have on their lives. (Pete, cleft)

Participants relayed their distress at these thoughts, their relief at finding this was not a reality and, in one case, the considerable distress and guilt they associated with their child having the same condition. One participant spoke of making a decision not to have children because of heritability and another recounted a level of uncertainty about whether they would have continued with the pregnancy had their child been found to share their condition. Most participants, however, discounted this possibility:

We did quite a bit of making sure that it was checked during the scans and when the girls were born, just so we were prepared and we were aware of it and it was checked out so that we could be kind of prepared and plan for it rather than we would necessarily have done anything different. (Anthony, cleft)

These comments imply that some participants understood the termination of pregnancy as one potential course of action that needed to be considered, even if immediately dismissed. This may speak to the "sort of unspoken eugenics" (Pauline, ichthyosis) that one participant felt society encouraged.

### **Looks Help Delineate and Define Relationships**

This final theme encapsulated understandings that participants' romantic relationships and visible difference could positively interact, with visible difference carrying the potential to improve romantic relationships.

**Assessing romantic partners by their reactions.** Just over half the participants (13 of 22) spoke about the reaction of a romantic partner to their visible difference functioning as a test or acting as a barometer of that person's character. This was often but not exclusively contemplated in connection with a disclosure scenario. This process was perceived as enabling participants to make a judgement about the likelihood of a relationship progressing based upon the reaction and response to their difference:

Part of me would think more of them as a person if, if they didn't have an issue with it, if they were still willing to try and get to know me as a person... I would think that that would make me have a much more positive attitude toward them so hopefully, even if I wasn't thinking that physically that they were my cup of tea, I would hope that that, in itself, that their attitude would change the way that I would be thinking about them. (Michelle, alopecia)

Where partners or potential partners did not provide an accepting and supportive response, or when an overtly negative reaction was anticipated or experienced, the reaction was seen as reflecting negatively on that other person:

Obviously if anyone did react negatively you'd know that they were an idiot so you wouldn't give them the time of day after that anyway! (Chloe, facial birthmark)

Although many participants had spoken about visible difference reducing their own self-worth, self-confidence, and value as a partner and had acknowledged that prevailing appearance ideals worked to their disadvantage, they expected potential

partners to react with compassion and understanding to their difference. Adverse reactions were considered unreasonable and as a sign of superficiality, detracting from the other person's worth.

**Enriching and fortifying relationships.** This sub-theme featured in 18 of the 22 accounts. Building on ideas introduced in the previous theme, participants argued that when their relationships progressed beyond the early stages, they became deeply rewarding and personally enriching as participants could:

Know that you're, that you have been taken as the whole package, warts and all, is, is a very wholesome feeling. To know that... somebody that has asked you to spend the rest of your life with them... it is quite something. And it is nice to know that they see through the outer crust of you and right into your heart and soul and mind. (Eleanor, psoriasis)

This sense of acceptance encouraged participants' belief in the legitimate, enduring, and robust nature of their relationships. Furthermore, the challenges an appearance-altering condition could present were considered adversities that could be overcome together, strengthening intimate interpersonal bonds. Visible difference was thus understood to offer some opportunity to develop durable, resilient, and sincere relationships. This was directly contrasted with relationships founded upon physical attraction:

At the end of the day, looks don't matter. It's what the person's like inside... When you get old and crumbly all you've got left is friendship and the people who would look beautiful and haven't developed a friendship with their partners, I think are the ones who split up. (Pauline, ichthyosis)

Participants also offered recognition of an indirect mechanism through which their appearance positively impacted their relationships. This was a perceived effect

upon their own personal characteristics, which included increased independence, strength, resilience, and openness. In turn, this influenced their ability to engage in rewarding relationships:

Being born with a cleft has certainly had an influence on how I am now as an adult. I do think it's had an influence on who I am and that's probably been to an extent fairly positive in that colours the way I approach things and stuff. I think my cleft has made me who I am and that led to us having our relationship.

(Anthony, cleft)

**Receiving treasured support.** This sub-theme was discussed by every participant. Whilst participants suggested that anybody without a visible difference cannot truly comprehend their experience, they valued the emotional support, companionship, security, protection, and encouragement towards engagement in activities that a romantic partner could offer:

To me, once you're in a relationship, and you know it was a reasonably meaningful relationship, then you know, you can forget that issue because you've got that person, the person's with you and you've been supported... so, to my mind once that's got the relationship then the disfigurement more or less disappeared. (David, cleft)

Participants spoke about their partners not seeing or caring about their difference. This was generally considered positive, to have assisted the development of the relationship and helped the participant to fully engage with the wider world. It could, however, hinder communication within a relationship, as it made it more difficult to acknowledge the impact of visible difference upon that relationship. In examining the prolonged sexual abstinence in her relationship, Karen described how

she had not discussed this with her partner despite her evident concern and uncertainty regarding whether her partner continued to find her sexually attractive:

I suppose it was me thinking “Oh he must see me differently, he’s never going to want me again” and then maybe he didn’t or maybe he did think that... I don’t know if he sees me in the same way but I’ve never spoken to him about it, which is quite bad really. I think I should. (Karen, breast cancer)

This was compounded by participants’ experiences with the healthcare profession. Their interactions with medical professionals were presented as being characterised by a lack of support and understanding regarding the experience of living with a visible difference:

In terms of what’s offered it’s been entirely physical and medical. When I revisited the doctor, a month or two ago now, she actually asked me a couple of questions. “Has it affected me?” “Do I, has it affected my confidence or anything?” So that was the extent that it was only a couple of questions and there was no “OK, if you wanted to talk to someone here’s the number,” or something. It was very clinical. (Ryan, facial palsy)

This extended into the realm of romantic relationships and participants’ intimate lives:

Just be a bit more sympathetic, you know. I was 37 and I still had hopes of getting married and having a family and he [the Doctor] basically told me that “You’ve got no hair, it’s not going to come back so deal with it.” (Ruth, alopecia)

The three female participants who had mastectomies and breast reconstructions as part of their treatment all reported dissatisfaction with the approach of the healthcare profession. Their testimonies suggested that they were unhappy with

the level of professional support available. Furthermore, healthcare staff failed to fully appreciate the psychosocial impact of their altered appearance and the potential for their romantic relationships and sexual lives to be adversely affected:

I think the thing was that they would make you look ok in a bra and that's kind of always stuck with me. When I thought they were just going to scoop all the gubbins out and put an implant in and stitch you back up and when they say "No, we will just make you look OK in a bra." I don't want to just look OK in a bra, you know? (Jodie, breast cancer)

In light of the difficulty experienced in discussing such issues within a relationship, the perceived lack of professional support, and the belief that others may not fully comprehend how it feels to live with a difference, participants identified peer-to-peer and expert-patient led interactions as the most preferable mechanism for delivering and receiving effective structured support:

If they did like a, you know, they had a self-help group going on, if you like, and, you know, you could talk to them people too because they're all probably going through the same thing but, as I say, you can't really talk about the intimacy too much to your friends because they could get embarrassed as well. (Valerie, facial palsy and breast cancer)

## **Discussion**

This study represents the first qualitative exploration of romantic relationships for adults with a visible difference that is not limited to a specific condition or group of medically or physically similar conditions. Drawing on qualitative data from 22 participants with a variety of conditions the findings demonstrated that participants understood their appearance and their romantic lives to be inexorably connected and that this association could endure through the lifespan of a relationship.

Participants' accounts of the formation and early stages of romantic relationships were characterised by concerns regarding the negative evaluation and judgments of others. These arose in connection with the initial judgments of potential partners and the moment of revelation or disclosure of a difference. The supposition that visible difference set participants apart from others indicated that, for this study population, a visible difference constituted a stigmatising characteristic. Participants had experienced both felt and enacted stigma (Scambler & Hopkins, 1986) in connection with their appearance. This took the form of feelings of being negatively judged and assessed as a potential partner, anticipatory anxiety prior to disclosure, and the actual negative reactions of others. The considerable anxiety induced by the disclosure scenario can be conceptualised as resulting from participants' contemplation of the voluntary but necessary transition from being discreditable by their existing-but-unknown stigmatised characteristic to potentially being discredited by a known stigmatised trait (Goffman, 2000).

Anxieties subsisting in anticipation of the moment of disclosure may be attributed to the negative consequences of concealment. These include the threat of the stigmatised condition being discovered, and the fear of revelation to a significant other (Clarke, Thompson, Jenkinson, Rumsey, & Newell, 2014). Such anxieties may arise as a result of the intrusive thoughts predicted by the preoccupational model of secrecy (Lane & Wegner, 1995). This model posits that secrecy promotes thought suppression and that such suppression leads to intrusive thoughts before renewed efforts at suppression and a cyclic repetition of intrusion and suppression. This model that has been shown to be relevant to other stigmatised conditions (Smart & Wegner, 1999) and its applicability to those with visible difference should be further explored.

The analysis indicated that participants internalised appearance expectations and ideals together with the negative connotations associated with visible difference.

Internalised appearance standards may have contributed to the perception of stigma and to experiences of it, in both its felt and enacted form (Scambler & Hopkins, 1986). Kent and Thompson (2002) described a process in which social signals regarding the distinctive and defective nature of one's appearance help form internal and external shame schemas in which the individual appraises themselves as inadequate and believes that others will reject them or discriminate against them. This can lead to feelings of shame and anxiety as well as cognitive distortions and automatic negative thoughts. These cognitive distortions may include hypervigilance to the reactions of others and interpretative biases (Kent, 2000; Thompson, Kent, & Smith, 2002). It is thus conceivable that the internalisation of social standards of appearance may have contributed to experiences of felt stigma and to cognitive biases in which incidences of enacted stigma are more readily interpreted.

The devaluation and discounting of the self by the participants was consistent with the internal shame schema proposed by Kent and Thompson (2002). This provided evidence of negative self-concept and echoed the accounts of young men with testicular cancer who considered themselves “damaged goods” as a result of the physical sequela of their cancer (Carpentier et al., 2011). The explicit possibility of compensating for this perceived deficiency evidenced an intuitive knowledge of the “mating market” in which an individual's characteristics and qualities may strengthen or weaken their bargaining power and dictate how their own demands and preferences may need to be adjusted as romantic and physical partnerships are formed (Swami, 2016). Whilst the most obvious consequence of participants devaluing themselves in this way related to the formation of relationships, it was apparent that this had the potential to help sustain unrewarding and even damaging relationships as some participants felt that their opportunities to negotiate alternative options were curtailed by their appearance.

In common with the findings of Mathias and Harcourt (2014), the initial reaction of a partner to participants' below-the-knee amputations was considered a screening mechanism or filter of potential partners and relationships. Such responses were typically, but not uniquely, contemplated within the context of a disclosure scenario. Crucially, participants conceptualised the real and imagined negative responses of potential partners as being indicative of the character of that other person rather than reflective of participants' innate value as a romantic partner and so, within this context, were able to detach themselves from the internal shame schemas proposed by Kent and Thompson (2002). Thompson and Broom (2009) identified a similar tendency as they found that participants with visible differences attributed the negative behaviours of others to the negative attributes of those other persons. The authors interpreted this as a self-protective strategy, utilised to decrease the emotional discontent experienced as a result of negative reactions by making external rather than internal attributions. Their work was not, however, concerned with the reactions of potential partners and the current research suggests that some participants in this study also employed this protective strategy within the romantic domain.

Evidence of these external attributions was drawn primarily from the participants' contemplation of the specific reactions (real or imagined) of new or potential partners to their difference, contained within the sub-theme "Assessing Romantic Partners by their Reactions." The sub-theme "Appearances are Central to Attraction" demonstrated that participants understood others, more broadly, to appraise them and their attractiveness based upon their appearance. Furthermore the related sub-theme "The Discounted Self" suggested these value judgements had been internalised and participants considered themselves personally devalued by their visible difference. Further research should examine whether external attributions may

protect against experiencing appearance distress in connection with romantic relationships, feelings of attractiveness, and one's value as a partner.

The ongoing impact of visible difference upon established relationships was evident from participants' anxiety about their partners perceiving their difference during sexual activity, the avoidance of such activity, and the concealment of their difference from their partners during intimate moments. This supports the contention of Batty, McGrath, and Reavey (2014) that failing to live up to normative notions of health and beauty can be disruptive to sexual encounters and that such strategies represent attempts at removing the salience and immediate visibility of the perceived deficiency. Furthermore, this indicates the potential relevance of the spectating phenomena (Masters & Johnson, 1970) to those with visible difference. As with that phenomena, participants spoke of being overtly conscious of the affected part of their body and this awareness impacting upon their sexual activity, implying some overlap between the study of body image and visible difference within the domain of appearance and sexuality.

Moving away from sexual activity, the suggestion that the presence of a visible difference could help strengthen established romantic relationships reinforces the propositions of Egan and colleagues (2011) in two ways. First, the belief that romantic relationships can benefit indirectly from the positive personal growth facilitated by a visible difference adds specificity to their claim that such growth can extend into improved relationships with others. Furthermore, Egan and colleagues (2011) identified the support, understanding, and acceptance of partners as being particularly important to their participants' sense of having adjusted positively to their difference. Participants in the current study evidenced this when they expressed belief in the legitimacy, sincerity, and durability of their romantic relationships with such beliefs being engendered by caring and compassionate partners. Their testimony

solidified ideas expressed by single women with breast cancer, who anticipated experiencing a sense of confidence that a new partner would be interested in them as a person and not just because of how they look (Ginter & Braun, 2017). This resembles the unconditional acceptance of one's body by family, partners, and friends that has been cited as a characteristic that helps promote and maintain positive body image (Tylka, 2012; Tylka & Wood-Barcalow, 2015).

The existing visible difference literature demonstrates that the nature, severity, and size of a difference are not strong predictors of adjustment (Moss, 2005; Ong et al., 2007, Rumsey et al., 2003, 2004). The present research, however, indicated that the experiences of those with visible differences that are not immediately obvious to others may vary in some respect from those that are more evident. "The Disclosure Dilemma" presented a unique challenge to those whose difference was not immediately apparent or could be concealed. The data also signalled that appearance, romantic relationships, and physical intimacy were understood as particularly salient issues for those affected in more highly sexualised areas of the body (such as the breasts) or those strongly associated with femininity (such as the hair). As this research does not permit conclusive comparisons to be made between sub-groups of the participants, further research could investigate the impact of visibility, sex, and the area of the body affected by a difference upon experiences of romantic relationships and sexual activity.

## **Limitations**

Whilst this research provided novel insights into experiences of visible difference and romantic relationships, its limitations must be acknowledged. The participants were heterosexual and spoke primarily about traditional monogamous relationships. Other sexualities and relationships are therefore not represented in the data. This was not by design but a function of those responding to the advertisements

for the study. Participants were primarily drawn from those that have some connection with support groups and charities that exist for those with an altered appearance. It is possible that respondents with these connections, or who, at a minimum, monitor the media of support groups and charities, may differ as a group from those that do not. For example, such individuals may experience their difference as more personally salient than others.

Participants were aware of the focus of this research and this awareness may have influenced potential participants' decisions concerning whether they wished to participate. Those who considered their difference to have exerted a significant impact upon their romantic lives may have been more likely to volunteer to be interviewed, with those who do not understand their difference as having exerted this impact potentially being underrepresented in the data. Similarly, only individuals who self-identified as having a visible difference were interviewed. Whilst this is consistent with the subjective nature of visible difference, it does mean that those with an appearance-altering condition or an altered appearance who do not self-identify in this way remain unrepresented.

The research project attracted a greater number of women than men. Whilst the experiences of men were captured, it is plausible that the relative lack of male representation influenced the nature of the analysis. It is also conceivable that having a male researcher conduct the interviews could have impacted potential participants' decisions about whether to engage with the research. Furthermore, participants' willingness to discuss issues of gender, sex, and sexual activity together with the researcher's receptiveness to such topics may have been partially shaped by dynamics of gender. Whilst six participants (five women and one man) spontaneously informed the researcher that they had never told anyone else about some of the experiences and thoughts that they discussed in the interviews or that they had not spoken about them

with their partners or with family members, it is not possible to be certain that all participants were so candid nor to know what else participants may have disclosed to another researcher. Future research concerning related topics may benefit from offering participants a choice between researchers of different sexes and with different gender identities.

The interviewer did not consider himself to have a noticeable visible difference and did not indicate otherwise to the participants. It is possible that, like his sex, this aspect of the researcher's identity had a salient impact upon the nature and content of his interactions with participants. Indeed, a number of participants expressly stated that it is very difficult for someone without a visible difference to fully empathise and understand the experience of someone with a visible difference. This may have been especially relevant to the five face-to-face interviews and the two conducted via Skype where the researcher's visible identity may have been more prominent. There is value in reiterating, however, that the participants interviewed via these more visual mediums of communication explicitly chose to interact with the researcher in these ways and had the option for their interviews to be conducted via the telephone.

The data were collected, coded, and analysed by the first author. This process was undertaken in line with guidance relating to the active and reflexive nature of the chosen analytic strategy. The analysis was the subject of on-going review, discussion, and agreement with the co-authors and a summary of the analysis was provided to the participants for comment. The chosen approach does not, however, include any formal metric to confirm the reliability of the analysis and so it is not possible to provide Cohen's kappa in order to gauge and evidence inter-rater reliability.

## **Conclusion**

This work focussed upon the under-researched intersection of visible difference and romantic relationships. Whilst participants considered visible difference to have positively impacted and strengthened some aspects of their relationships, appearance related concern and distress were evident. These were manifest as concerns relating to the judgements and perceptions of others, in participants' assessment of their own value as a partner, and in their descriptions of the disclosure of a visible difference to a romantic partner. Furthermore, anxieties related to sexual activity and physical intimacy, apprehensions connected to the heritability of some appearance-altering conditions, and dissatisfaction with the unavailability of effective support mechanisms, were all expressed. The identification of these negative consequences implicates engagement in romantic relationships as an area of activity which should be addressed by future psychosocial interventions designed for adults with visible difference. Furthermore, work to raise awareness amongst healthcare professionals and to promote skills and resources to facilitate effective support may also prove beneficial.

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Table 1

*Semi-Structured Interview Guide Questions*

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Questions

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Could you say something about any experiences you have of very close, intimate relationships?

Are there any ways in which appearance is important to intimate/romantic relationships?

Would you be able to describe any ways in which your appearance has impacted upon these relationships or this aspect of your life?

What do you think are the important factors in explaining why your appearance has affected you in this way?

What would it take to reduce or remove (or, if positive impact, sustain) this impact?

Could you say anything about whether you have engaged in any specific behaviours or taken any action to reduce or alter any such impact upon your intimate life?

Could you describe the behaviour of your partners or potential partners in connection with your appearance?

How do you feel your partners or potential partners feel or felt about your appearance?

How do you imagine your intimate life would be different if you did not have your visible difference?

How do you feel about the future of your intimate relationships?

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Table 2

*Romantic Relationships and Intimacy Themes, Subthemes, and Example Codes*

Theme	Subtheme	Example codes
Appearance Attracts and Detracts	Appearances are central to attraction	Assessed on looks Women's appearance crucial
	The discounted self	Personal deficiency Compensate for appearance
Looking Different: Physicality and Physical Reality	The disclosure dilemma	Uncertainty over revelation Partner reaction to reveal
	Invading physical intimacy	Avoidance of sex Sexual preoccupation
	Concerns over the heritability of appearance-altering conditions	Pass appearance on Impact my child
Looks Help Delineate and Define Relationships	Assessing romantic partners by their reactions	Response sends message Judge partner on response

Enriching and fortifying  
relationships

Appearance is shallow  
Galvanised me

Receiving treasured support

Partner protective  
Lack support

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