PROFESSIONAL DOCTORATES

Autism and Gender

An exploration of high-functioning autism in females

Hooper, Aimee

Award date:
2016

Awarding institution:
Bangor University

Autism and Gender: An exploration of high-functioning autism in females

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Bangor University

Thesis submitted in partial fulfilment for the Degree of Doctorate in Clinical Psychology

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Section One

Thesis Abstract

Autism and Gender: An exploration of high-functioning autism in females

This thesis comprises of the following three papers: (1) a systematic literature review; (2) a qualitative empirical study; (3) contributions to theory and clinical practice.

The systematic literature review qualitatively summarises 17 papers dated 2013–2015, exploring possible gender differences in young individuals with autism aged 0–18 years old. The results, although mixed due to variability and limitations in study design and methodology, suggested that young individuals with autism may be more similar than dissimilar in the severity of their core autism symptomatology. However, there may be autism-specific gender differences in the following areas: neurobiological abnormalities; sensory sensitivity; parental distress; the quality and nature of restrictive and repetitive behaviours, interests and activities; and the co-morbidity of other conditions. The clinical and research implications are discussed in detail.

The empirical paper presents an original qualitative exploration of 11 high-functioning autistic women's lived experiences, aged 19–60 years old, around their use or non-use of coping strategies in social situations. A thematic analysis of interview transcripts suggested that the women used various methods to get by socially. The types of strategies reported were either to mask social skills difficulties and autistic behaviours, or, to compensate for certain social skills limitations. Alternatively some of the women had dropped previously used 'acts' and others had never wished to compensate or mask, preferring to be open and honest. Regardless of the coping approach used, the women experienced more negative outcomes than positive ones from their social experiences. The clinical and research implications of these findings are explored.

The third paper discusses the theoretical, clinical, and research implications of the above papers in further detail.

Declarations

This work has not been previously accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

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Date ……

Statement 1

This thesis is the result of my own investigations, except where otherwise stated. Other sources are acknowledged by footnotes giving explicit references. A list of references is appended.

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Date ……

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Acknowledgements

The author would like to thank the participants who kindly took part in this study without whom the project would not have been possible, and also the professionals who supported the vital recruitment stages of the project.

Thanks go to Dr Kristina Cole for her guidance, support and advice throughout all phases of the thesis journey, giving up a lot of her own time. Her kindness and support throughout was invaluable. The author would also like to thank staff members of the clinical programme for their guidance and support.

Finally, the author gives thanks to her husband whom from their home in Devon has supported her unconditionally throughout her training to date and during the thesis write-up. Thanks also go to Audrey White, in whose memory this thesis is dedicated – she wanted the author to continue to strive towards becoming a clinical psychologist and this thesis is a key part of that journey.

Section Two:

Literature Review

Are boys and girls on the autistic spectrum really that different? A systematic review updating the current autism gender literature on children and adolescents.

Aimee J Hooper

North Wales Clinical Psychology Programme, School of Psychology, Bangor University, North Wales

Betsi Cadwaladr University Health Board, North Wales

Kristina Cole

Betsi Cadwaladr University Health Board, North Wales

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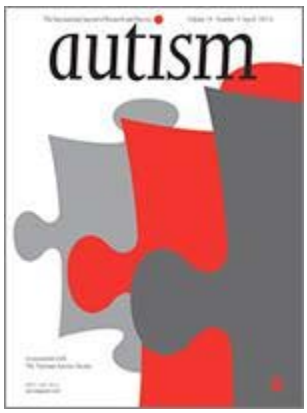
Author Submission Guidelines



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Autism

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2014 Impact Factor: 3.639

2014 Ranking: 10/68 in Psychology, Developmental

Source: 2014 Journal Citation Reports ® (Thomson Reuters, 2015)

The National Autistic Society

- SUBMISSION GUIDELINES

1. **Editorial Policies**

Autism provides a major international forum for research of direct and practical relevance to improving the quality of life for individuals with autism or autism-related disorders.

1. Editorial policies

1.1 Peer review policy

Autism operates a strictly anonymous peer review process in which the reviewer's name is withheld from the author and, the author's name from the reviewer. The reviewer may at their own discretion opt to reveal their name to the author in their review but our standard policy practice is for both identities to remain concealed. Each new submission is carefully read by one of the Editors to decide whether it has a reasonable chance of getting published. If the Editor thinks it does not have this chance, at least one other Editor will be consulted before finally deciding whether or not to send the manuscript out for review.*Autism* strives to do this within two weeks after submission, so that authors do not have to wait long for a rejection. Feedback is also provided on how to improve the manuscript, or what other journal would be more suitable. Each manuscript is reviewed by at least two referees. All manuscripts are reviewed as rapidly as possible, and an editorial decision is generally reached within (e.g.) 6-8 weeks of submission.

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To comply with the guidance for Research Funders, Authors and Publishers issued by the Research Information Network(RIN), *Autism* additionally requires all Authors to acknowledge their funding in a consistent fashion under a separate heading. All research articles should have a funding acknowledgement in the form of a sentence as follows, with the funding agency written out in full, followed by the grant number in square brackets:

This work was supported by the Medical Research Council [grant number xxx].

Multiple grant numbers should be separated by comma and space. Where the research was supported by more than one agency, the different agencies should be separated by semi-colon, with “and” before the final funder. Thus:

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Autism and SAGE take issues of copyright infringement, plagiarism or other breaches of best practice in publication very seriously. We seek to protect the rights of our authors and we always investigate claims of plagiarism or misuse of published articles. Equally, we seek to

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3. Article types

The Journal considers the following kinds of article for publication:

1. **Research Reports.** *Full papers* describing new empirical findings;

2. **Review Articles.**
(a) general reviews that provide a synthesis of an area of autism research;
(b) critiques - focused and provocative reviews that may be followed by a number of invited commentaries, with a concluding reply from the main author.
Both full Research Reports and Review Articles are generally restricted to a maximum of

6,000 words, including all elements (title page, abstract, notes, tables, text). Editors may ask authors to make certain cuts before sending the article out for review.

3. **Short Reports.** Brief papers restricted to a maximum of 2,000 words with no more than two tables and 15 references. Short reports could include other approaches like discussions, new or controversial ideas, comments, perspectives, critiques, or preliminary findings. The title should begin with 'Short Report'.

4. **Letters to the Editors.** Readers' letters should address issues raised by published articles. The decision to publish is made by the Editors, in order to ensure a timely appearance in print. Letters should be no more than 800 words, with no tables and a maximum of 5 references.

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4. How to submit your manuscript

Before submitting your manuscript, please ensure you carefully read and adhere to all the guidelines and instructions to authors provided below. Manuscripts not conforming to these guidelines may be returned.

Autism is hosted on SAGEtrack a web based online submission and peer review system powered by ScholarOne Manuscripts. Please read the Manuscript Submission guidelines below, and then simply visit http://mc.manuscriptcentral.com/autism to login and submit your article online.

IMPORTANT: Please check whether you already have an account in the system before trying to create a new one. If you have reviewed or authored for the journal in the past year it is likely that you will have had an account created. For further guidance on submitting your manuscript online please visit ScholarOne Online Help.

All papers must be submitted via the online system. If you would like to discuss your paper prior to submission, please refer to the contact details below

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5. Declaration of conflicting interests

Within your Journal Contributor's Publishing Agreement you will be required to make a certification with respect to a declaration of conflicting interests. *Autism* does not require a declaration of conflicting interests but recommends you review the good practice guidelines on the SAGE Journal Author Gateway.

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6. Other conventions

We would prefer to use the term ‘people with autism’ or ‘people with autism spectrum disorders or conditions’. We would also prefer the term ‘typically developing’ rather than ‘normal’.

6.1 Research ethics

All papers reporting animal and human studies must include whether written consent was obtained from the local Ethics Committee or Institutional Review Board. **Please ensure that you have provided the full name and institution of the review committee and an Ethics Committee reference number.**

We accept manuscripts that report human and/or animal studies for publication only if it is made clear that investigations were carried out to a high ethical standard. Studies in humans which might be interpreted as experimental (e.g. controlled trials) should conform to the Declaration of Helsinki http://www.wma.net/en/30publications/10policies/b3/index.html and typescripts must include a statement that the research protocol was approved by the appropriate ethical committee. In line with the Declaration of Helsinki 1975, revised Hong Kong 1989, we encourage authors to register their clinical trials (athttp://clinicaltrials.gov or other suitable databases identified by the ICMJE, http://www.icmje.org/publishing_10register.html). If your trial has been registered, please state this on the Title Page. When reporting experiments on animals, indicate on the Title Page which guideline/law on the care and use of laboratory animals was followed.

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Authors are required to ensure the following guidelines are followed, as recommended by the International Committee of Medical Journal Editors, Uniform Requirements for Manuscripts Submitted to Biomedical Journals. Patients have a right to privacy that should not be infringed without informed consent. Identifying information, including patients' names, initials, or hospital numbers, should not be published in written descriptions, photographs, and pedigrees unless the information is essential for scientific purposes and the patient (or parent or guardian) gives written informed consent for publication. Informed consent for this purpose requires that a patient who is identifiable be shown the manuscript to be published.

Identifying details should be omitted if they are not essential. Complete anonymity is difficult to achieve, however, and informed consent should be obtained if there is any doubt. For example, masking the eye region in photographs of patients is inadequate protection of anonymity. If identifying characteristics are altered to protect anonymity, such as in genetic pedigrees, authors should provide assurance that alterations do not distort scientific meaning and editors should so note. When informed consent has been obtained it should be indicated in the submitted article.

6.3 Statistical analyses

Where statistical analyses have been carried out please ensure that the methodology has been accurately described. In comparative studies power calculations are usually required.

In research papers requiring complex statistics the advice of an expert statistician should be sought at the design/implementation stage of the study.

6.4 Randomized controlled trials

Autism requires a completed CONSORT 2010 checklist and flow diagram as a condition of submission when reporting the results of a randomized trial. Templates for these can be found on the CONSORT website [www.consort-statement.com] which also describes several CONSORT checklist extensions for different designs and types of data beyond two group parallel trials. You should ensure that your article, at minimum, reports content addressed by each item of the checklist. Meeting these basic reporting requirements will greatly improve the value of your trial report and may enhance its chances for eventual publication.

6.5 Prisma

Autism requires a completed PRISMA checklist and flow diagram as a condition of submission when reporting the results of a systematic review. Templates for these can be found on the PRISMA website www.prisma-statement.org. You should ensure that, at minimum, your article reports content addressed by each item of the checklist. Meeting these basic reporting requirements will greatly improve the value of your systematic review and may enhance its chances for eventual publication.

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8.1 File types

Only electronic files conforming to the journal's guidelines will be accepted. Preferred formats for the text and tables of your manuscript are Word DOC, RTF, XLS. LaTeX files are also accepted. Please also refer to additional guideline on submitting artwork and supplemental files below.

8.2 Journal Style

Autism conforms to the SAGE house style. Click here to review guidelines on SAGE UK House Style.

8.3 Reference Style

Autism operates a Sage Harvard reference style. Click here to review the guidelines on SAGE Harvard to ensure your manuscript conforms to this reference style.

8.4. Manuscript Preparation

The text should be double-spaced throughout and with a minimum of 3cm for left and right hand margins and 5cm at head and foot. Text should be standard 10 or 12 point. SI units should be used throughout the text.

8.4.1 Terms for Autism

UCL and NAS conducted a survey within the UK of stakeholders connected to autism, to enquire about preferences regarding the use of language. Based on the survey results, we have created guidelines on terms which are most acceptable to stakeholders in writing about autism here.

8.4.2 Keywords and Abstracts: Helping readers find your article online

The title, keywords and abstract are key to ensuring that readers find your article online through online search engines such as Google. Please refer to the information and guidance on how best to title your article, write your abstract and select your keywords by visiting SAGE's Journal Author Gateway Guidelines on How to Help Readers Find Your Article Online.

8.4.3 Corresponding Author Contact details

Provide full contact details for the corresponding author including email, mailing address and telephone numbers. Academic affiliations are required for all co-authors. These details should be presented separately to the main text of the article to facilitate anonymous peer review.

8.4.4 Guidelines for submitting artwork, figures and other graphics

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8.4.5 Guidelines for submitting supplemental files

This journal is able to host approved supplemental materials online, alongside the full-text of articles. Supplemental files will be subjected to peer-review alongside the article. For more information please refer to SAGE's Guidelines for Authors on Supplemental Files.

8.4.6 English Language Editing

Non-English speaking authors who would like to refine their use of language in their manuscripts might consider using a professional editing service. Visit English Language Editing Services for further information.

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9. After acceptance

9.1 Lay Abstracts
Upon acceptance of your article you will be required to submit a lay abstract of your article to the Social Media Editor, Laura Crane (journalautism@gmail.com). Lay abstracts are brief (max 250 words) descriptions of the paper that are easily understandable. These abstracts will be made available to researchers and clinicians, as well as the general public (including individuals with autism spectrum disorders and their families).

These abstracts should avoid both technical terminology and the reporting of statistics. Examples of lay abstracts are provided in recent issues of the journal.

9.2 Proofs
We will email a PDF of the proofs to the corresponding author.

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SAGE provides authors with access to a PDF of their final article. For further information please visithttp://www.sagepub.co.uk/authors/journal/reprint.sp.

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Any correspondence, queries or additional requests for information on the Manuscript Submission process should be sent to the Editorial Office as follows:

Katie Maras
Department of Psychology

University of Bath, UK
Email: katiemaras.autism@gmail.com

Terms for autism:

Earlier this year UCL and NAS conducted a survey within the UK of stakeholders connected to autism, to enquire about preferences regarding the use of language. Based on the survey results, we have created guidelines on terms which are most acceptable to stakeholders in writing about autism. Whilst these guidelines are flexible, we would like researchers to be cognisant of the preferences expressed to us by the UK autism community.

Preferred terms

Amongst autistic adults, the term 'autistic person/people' was the most commonly preferred term. The most preferred term amongst all stakeholders on average was 'people on the autism spectrum'.

Terms not preferred:

1. **Suffers from OR is a victim of autism:** consider using the following terms instead:

    - is autistic
    - is on the autism spectrum
    - has autism / an autism spectrum disorder (ASD) / an autism spectrum condition (ASC)
      (Note: The term ASD is used by many people but some prefer the term 'autism spectrum condition' or 'on the autism spectrum' because it avoids the negative connotations of 'disability' or 'disorder'.)

2. **Kanner's autism**

3. **Asperger's syndrome is a rare / mild form of autism**

4. **autism is a disease / illness:** consider using the following instead:

    - autism is a disability
    - autism is a condition

5. **retarded / mentally handicapped / backward:** These terms are often considered to be derogatory and offensive by members of the autism community and we would advise that they not be used.

6. **normally developing children:** consider using the following terms instead:

    - neurotypical

(Note: This term is only used within the autism community so may not be applicable in, for example, the popular press.)

- typically developing children
- Some people refer to themselves and one another as an autist / autie / aspie. Whilst we accept that people may wish to refer to themselves and each other in this way, it is often less acceptable when used by a 'neurotypical' person.

7. **Low or High Functioning:**

Many autistic adults and family members though that dividing autistic people into low or high functioning did not fully represent the rich pattern of ability and challenges faced by individuals. We would encourage a more precise description of people's abilities (such as cognitive or verbal ability).

SAGE UK Style Guide

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2. Article opening material

2.1 Headings

1. Headings should have an initial capital with everything else lowercase, unless proper names.
2. Italics can be included in A heads (H1) if needed, e.g. mathematical symbol or genus name.
3. Headings are unnumbered and formatted as below.
4. Where headings are referred to in the text use section names, as headings are not numbered.

A head (H1) (bold with initial cap, all the rest lowercase)

Introduction

The mucosa of the small and large intestines is the largest reservoir of tissue macrophages (Mϕ) in both humans and mice.[1] Although Mϕ possess various

B head (H2) (Italic with initial cap, all the rest lowercase)

Human samples

Human specimens of normal large intestine were obtained from normal tissues of three patients with colon cancer who had their large intestine resected for

C head (H3) (same as B head, but set as first line of paragraph, full out; Italic with initial cap, all the rest lowercase, followed by a full stop. Following text runs on)

Single nucleotide primer extension. The PCR product from bisulfite-treated genomic DNA was cleaned with ExoSAP (USB) prior to SNuPE reaction. For calibra-

Headings for Abstract, Keywords, Funding, Acknowledgements, Conflict of Interest (in that order), References, Appendices are same as A head but smaller font size

Acknowledgements

We thank Dr van Lookeren Campagne (Genentech) for providing blocking mAb against CR3g (clone 8G8) and isotype control mAb (anti-ragweed).

(CEs: where a template is being used there is no need to format these. Where no template is being used, please format as bold/italic, but there is no need to mark the font sizes, TS will format.)

2.2 Article types

Where a journal displays article types, these should appear on the first page of each article, left aligned above the horizontal rule, and in italics.

General technical or research papers should be classified as *Original Article* (with uppercase initial caps) for STM, and *Article* for HSS. (Check with the PE, as there is some variation between journals.)

Other usual paper types are as follows: *Review Article*, *Case Study*, *Technical Note*, *Case Report*. Individual journals may also have other paper types, as agreed with the Editor. Where no particular convention has been agreed, *Original Article* should be followed for STM, and *Article* for HSS.

2.3 Article title

Please format with an initial capital only and remaining words lower case, unless proper names. Italics can be included where necessary (e.g. genus name). Run on subtitle after colon, with initial capital after colon.

2.4 Author names, affiliations, and corresponding address

Authors

List authors in the order that they appear on the manuscript. Authors' first name should be in full, middle names should be initials without full stops (e.g. Simon PS Sharma) and no spaces between multiple initials. No series comma before the 'and' before the final author name.

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Affiliations should contain only the following: department *or* faculty, institution, country. Some HSS journals may have institution and country only. Do not include titles, positions, qualifications, street names, or postcodes/zip codes. Affiliations should not end in a full stop.

STM: author names should be annotated with superscripted numbers (CE: do not use automated endnotes against names and affiliations). If all authors are at the same affiliation no superscript numerals are required. Affiliations appear separately with the corresponding address at the bottom of the right column (see next page):

Mark A Creager[1], Reena L Pande[1] and William R Hiatt[2,3]

HSS: affiliations should directly follow each author name, as follows:

Mark A Creager

(Department of Engineering,) Southampton University, UK

Reena L Pande

(Department of Engineering,) Southampton University, UK

William R Hiatt

County Hospital, CA, USA; Harvard Medical School, USA

Multiple affiliations are separated by a semi-colon.

Corresponding author

The affiliations and corresponding author information is positioned as follows:
Bottom of the right column on the first page of each paper, separated from the text with a horizontal rule (some exceptions apply for specific journals).

Corresponding author:
John Smith, Department of Social Studies, South Bank University, 4 Sample Road, London SE17 9OP, UK
Email: john.smith@sbu.ac.uk

STM: Affiliations and corresponding author details should appear as follows, bottom of right column.
HSS: corresponding author appears in the same position, minus the affiliations.

[1]Research Center Borstel, Leibniz-Center for Medicine and Biosciences, Borstel, Germany
[2]Microbiology Department, Chemical Faculty, Gdańsk University of Technology, Gdańsk, Poland
[3]Novartis, Basel, Switzerland

Corresponding author:
Sven Hiller-Loennies, Research Center Borstel, Leibniz-Center for Medicine and Biosciences, Parkallee 22, D-23845 Borstel, Germany.
Email: smil@fz-borstel.de

Please remove any fax or telephone numbers, titles (e.g. Dr, Professor), positions (e.g. Senior Lecturer).

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Please note: 'Email' with cap E and without hyphen. Email should start a new line. There *should* be a full stop after the country in the corresponding address.

Affiliations and corresponding address text should be left aligned, not justified, to avoid irregular spacing between words.

2.5 Abstract and keywords

Abstract should appear in bold without a colon, text should start on the next line, with no indent.

Keywords (all one word) should appear in bold without a colon. The keywords should start on the next line, separated by commas only, not semi-colons. The first keyword should have an initial cap.

Abstract

Anaphylaxis related to drug therapy with 5-HT3 antagonists, in particular, palonosetron has not been reported frequently in the literature. Here a case is presented where the patient possibly had an anaphylactic reaction to palonosetron. In this case report, a 40-year-old female with ovarian cancer developed shortness of breath and hypotension after receiving her palonosetron as part of her premedication for chemotherapy. The patient recovered successfully with fluids and supportive care. This case demonstrates that even after successful treatment in the past with palonosetron a patient may later develop a hypersensitivity to the agent.

Keywords

Palonosetron, anaphylaxis, hypersensitivity, 5-HT3 receptor antagonist

In some journals, Abstracts have sub-headings, e.g. Methods, Conclusion etc. These should be formatted in bold with a colon in bold and each sub-heading should start a new paragraph. The text should run on after each heading with an initial capital.

Submitted/accepted dates

For journals that publish received/revised/accepted dates (applies to specific journals, if unsure please check with the PE), this should appear after the Keywords and be formatted thus:

Date received 29 July 2010; reviewed 30 August 2010; accepted 5 November 2010

Keywords

HSN1, apoptosis, TRAIL, caspase-10

Date received: 30 March 2011; revised: 19 April 2011; accepted: 28 April 2011

2.6 Running heads

Recto: should be author surname(s), e.g. *Smith*, or *Smith and Jones*, or *Smith et al.* (for three or more authors, and et al. is also in italic).
Verso: full journal title in italic, followed by 0(0).
For IMechE journals: e.g. *J. Automobile Engineering 0(0)*, without the Proc. IMechE or journal letter).

Innate Immunity 0(0)

3. General style and layout

3.1 Logo and Imprint box

All papers in the standard SAGE design will have a journal logo in the top right with an imprint box underneath (although the logo may be missing on journals that are new to the SAGE design). The imprint box will contain the following information: journal name, vol/issue/page numbers (for papers in production, vol/issue are represented by 0(0), page numbers are the number of pages in the PDF, e.g. 1–9), copyright line, link to permissions web page, DOI, journal URL, SAGE logo:

3.2 Figures

1. STM: All figures should have a key line (i.e. be enclosed in a box). HSS: figures have no key line.
2. Figures should be appropriately sized (done by the TS). They do not need to be a full column width or page width.
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4. Source: In cases where permission is required and has been obtained, this should appear below the caption in the following form: Source: reproduced with permission from publisher, year, reference number (Vancouver), author, date (Harvard).
5. Any abbreviations needing to be spelled out should be listed after the caption, starting on the next line, in the following format: IC: internal combustion; PID: proportional–integral–derivative).
6. Captions are positioned below the figures and left aligned.
7. Captions should start, for example, **Figure 1.** (with a full point also in bold) and have a full point at the end. Where the text runs onto multiple lines, the captions need not be justified but should be aligned left.
8. Where figures have multiple parts, these should be labelled as (a), (b), (c), etc. (not A, B, C). Captions should contain subheadings for all parts if not present in the figure itself.
9. All figures should be numbered consecutively and cited in the text as Figure 1, Figure 2 etc. (Figure should be spelled out in full, not abbreviated).
10. Text citations: figures should be referenced in the text as follows: Figure 1, or Figures 1 and 2, or Figures 2 to 4, or Figure 1(a) and (b), or Figure 2(a) to (c). Where the figure citation is not part of the sentence it should be placed in parentheses.

Examples:
Please see Figure 2 for an illustration of the model used
The model used was an X3G standard type, exported from Germany (Figure 2 or see Figure 2).

3.3 Tables

1. Tables do not need to be a full column width or page width, but should be the appropriate width for the content. They will be laid out by the TS so no work is required by CEs on table layout, only on content.
2. Table headings should be left aligned, even when they relate to multiple columns, unless this creates confusion.

3. Tables should only have minimal horizontal rules for clarity, and no vertical rules (done by TS, no need for CE to format).
4. All tables should be numbered consecutively and cited in the text as Table 1, Table 2 etc. (Table should be spelled out in full, not abbreviated).
5. Table permissions: any tables reproduced from another publication need permission. In cases where those publishers listed on the STM permission Guidelines page (http://www.stm-assoc.org/permissions-guidelines/), permission is not required and only the reference number need by present in the caption. Some publishers ask for certain text, e.g. Elsevier.
6. Source: In cases where permission is required and has been obtained, this should appear below the table in the following form: Source: reproduced with permission from publisher, year, reference number (Vancouver), author, date (Harvard).
7. Any abbreviations needing to be spelled out should be listed under the table (smaller font, TS will format), in the following format: IC: internal combustion; PID: proportional–integral–derivative.
8. General notes to the Table should be positioned below the Table, typeset in a smaller font and should start 'Note:', and end in a full stop. Do *not* add the word 'Note:' unless needed for clarity.
9. Footnotes should be represented in the table by superscript letters [a], [b], [c], etc., and appear below the Table (smaller font, TS will format). Each footnote should start a new line and end with a full stop. These notes should precede the source for the table, if included.
10. Captions are positioned above the table and left aligned.
11. Captions should start, for example, **Table 1.** (with a full point also in bold) and have a full point at the end. Where the text runs onto multiple lines, the captions need not be justified but aligned left.
12. Dates in Tables can be shortened to, for example, 4 Dec 10, if space is lacking. Do not use the form 04/12/10, as this could be confused as 12 April in US.
13. Normal text in columns should always be left aligned. Data in tables should be aligned on units if all the data in that column take the same units. Otherwise, the data should be left aligned. Units in table headings should be enclosed by parentheses, not square brackets (if any brackets are required at all).

3.4 Lists

1. For lists where items are not full sentences, use (a), (b), (c) etc. or bullet points (whichever is more appropriate) and separate items with semi-colons. Start list with a preceding colon and end list with a full stop.
2. For lists where items are full sentences or multiple sentences, use 1. 2. 3. Start list with a preceding full stop or semi-colon (whichever is more appropriate), and end list with a full stop.
3. List numbering/bullets should be full out and left aligned, with text indented and aligned. Lists should be separated from preceding/following text with a line space.
4. Where list items include headings, that heading should be italic, same size as text and end in a full stop. The following text should run on.

3.5 Maths/equations (see section 5, p. 14 for more details)

1. Equations should be left aligned with a 3 mm indent, *not* centred.
2. Equations can be broken at operator symbols (x, -, +, etc.), and continue on the next line, starting with the operator itself.
3. Equations should be separated from text above and below by at least one line space.
4. Any equation numbers should be enclosed in parentheses and right aligned, and aligned horizontally with the bottom line of the equation or equations, where multiple terms are covered by one equation number. (Not all equations need be numbered, see section 5).

General note: text following Figures, Tables, equations does not need to be full out with no indent. If the next block of text after any of these items is a new paragraph, then this may be indented.

3.6 Appendices

Maths notation list

1. Where present, notation should appear as Appendix 1, following the references. The heading *Notation* should be a B-head (not Notations; it is not plural).
2. Abbreviations list should be separated from mathematical notation under a separate B-head *Abbreviations*.

3. Notation should be listed in alphabetical order, English letters first, followed by Greek, followed by numbers, followed by symbols.
4. Subscripts and superscript should come under a separate C-head (italic and smaller font), and symbols should follow the same order as in point 2 above.
5. The Notation section does not need to be cited in the text, like other Appendices.
6. Notation list should be left aligned. Text in the notation section should be left aligned in general, not justified.
7. Please note that a notation list is not compulsory in mathematical papers, as long as all symbols are defined in the text.

Other appendices

1. Numbering of figures/tables/equations in Appendices should follow on from the numbering in the text.
2. All tables/figures should have captions.
3. All appendices should be cited in the text, e.g. (see Appendix 1). If they are not cited, authors need to be queried for a citation position.

3.7 Notes and footnotes

Textual notes

HSS

References: Vancouver style reference citations are represented as textual notes, as a numeral enclosed in a square bracket. Harvard style references are as follows (Smith, 1999).
Any other textual notes: are indicated by a superscript Arabic numeral placed after the punctuation. All textual notes should be collected and placed after the text and before the reference section with the heading **Notes**.

STM

References: Vancouver style reference citations are represented as textual notes, as a superscript Arabic numeral. Harvard style references are as follows (Smith, 1999).
Any other textual notes (whether references are Harvard or Vancouver) are indicated by a superscript Arabic letter and the corresponding footnote appears at the bottom of the relevant column.
In STM journals, footnotes should be edited into the text if appropriately and easily incorporated. However, please leave footnotes if this is not possible.

Authors' biographical notes

These should appear at the end of the paper with the heading **Author biography** (or **biographies**), in same font size as References/Funding etc. heading. Follow journal style.

3.8 Book reviews

Please check that the book details are given in this format at the top of each review.

Author, title, publisher: place, date of publication; 000 pp.: ISBN, price (hbk), ISBN, price (pbk)
Editor(s) (ed[s].), title, publisher: place, date of publication; 000 pp.: ISBN , price (hbk), ISBN, price (pbk)

4. Spelling, punctuation and formatting

4.1 Author style/voice

We will endeavour to keep the author's voice as much as possible:

1. Some authors write in the first person. CEs please note that we will *not* be taking articles out of the first person into the third person.
2. Where American authors have used American spellings, we should also endeavour to keep the author's grammar/punctuation, e.g. closed em-dashes instead of spaced en-dashes, single quotation marks within double, series comma etc.
3. Where UK authors have used –ise spellings throughout their papers in a consistent fashion, please do not change. Where there is inconsistency, use -ize.

4.2 General spelling rules

The general rules are as follows:

- UK spellings should be followed for European articles (-ise is acceptable)
- US spellings should be followed for North American articles
- Rest of the world – follow author style but make it consistent
- Canadian spellings should be standardized to UK or US, depending on author preference
- The following list shows some common exceptions to the '-ize' rule:

Samples							
advertise	arise	devise	enfranchise	expertise	merchandise	promise	surmise
advise	chastise	disenfranchise	enterprise	franchise	misadvise	reprise	surprise
affranchise	circumcise	disguise	exercise	improvise	premise	revise	televise
apprise	comprise	emprise	excise	incise	prise	supervise	treatise

Note also: analyse (for UK), catalyse, dialyse, paralyse.

Do not mix English and US spellings. Some common US variations in spelling:							
analyze	color	favor	fulfil	labor	license (noun)	program	traveler/traveling
behavior	counseling	fetus	gray	mold	pediatrics	practice (verb)	willful

Follow author style regarding use of the possessive's for proper names ending in s. However, 's is not used for classical names, e.g. Socrates' philosophy.

The following books are recommended: *Hart's Rules*; *Fowler's Modern Usage*.

4.3 Punctuation and formatting

Commas

- Follow author style but make consistent
- Oxford or series comma are not generally used; only use an Oxford/series comma if essential for clarity

Parentheses

These can be used throughout. Double sets of parentheses are acceptable, e.g. (see Figure 2(a)). Do not use square brackets in the text, except in the following circumstances.

Square brackets are used only to enclose an author's comment within a quote, e.g. [sic], [emphasis added]. Square brackets are also used for equations and mathematical expressions within the text.

Quotes

Use single quotes, with double quotes within quoted material. (See section 4.1 for exceptions for articles written by US authors.)

Hyphenation

The basic rule is to follow author style but be consistent.

Use of upper and lower case

Check the author's usage first, and make consistent. For specific titles use initial caps, for generic titles use lower case (useful pointers follow):

Institutions, movements, denominations, political parties:

- the Roman Catholic Church
- he has catholic tastes
- They were Bolsheviks
- bolshevism, communism

Titles, ranks:

- the President (referring to a particular one)
- the Spanish Foreign Minister
- a president
- several government ministers

Geographical names:
Capitalize politically defined or geographically named places, use lower case in all other instances.

- the West, the East
- western values, eastern culture
- South Africa
- the south of Scotland

Periods, events:

- Second World War
- rationing during the war

Article and book titles:
Follow the style used in the references.

Roman and italic usage

- Anglicized words should be roman with no accents (common examples follow):

Samples			
ad hoc	coup d'etat	laissez faire	post mortem
a priori	de facto	nouveau riche	raison d'etre
a propos	elite	op. cit.	sine qua non
avant-garde	en masse	per annum	status quo
bona fide	en route	per capita	vice versa
bourgeois/bourgeoisie	et al.	per se	vis-a-vis
cafe	in situ	post hoc	

- Words in other languages – follow author style and make consistent.
- Keep author's own emphasized words or phrases (in italic), unless excessive.
- General: usual italic rules applies, e.g. genus, species, relevant mathematical symbols, *x*-axis, *y*-axis, journal/book/magazine names, etc.

Quoted text
Spellings and punctuation in quoted texts should not be altered. If they are obviously incorrect, query with author or insert [sic].

Undisplayed quotes:
Short quotations should be indicated by single quotation marks, with double quotation marks for quotation material within the quote. A full point (or other punctuation) follows the reference for the quote, e.g. '… is the most decisive and important' (Smith, 2003).

Displayed quotes:
Lengthy quotes (40 words or more) should be displayed and indented, with a line space above and below, separating it from the text – follow journal style. Font size will be smaller (TS to format).

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Money
For currency use the common symbol or abbreviation: £, US$, AUD$, etc. – where the quantity is stated, but not when the unit of currency is being referred to in general terms, examples follow:

- The price of oil rose to US$25 per barrel.
- The US dollar was at an all-time low.
- £150m, *not* millions or mins.

Units in the text

1. Where units are referred to in the text in general terms, they should be written out in full.
2. Where a specific quantity is used, the abbreviated form of the unit must be used; e.g. the nails were several centimetres long; the nails were each 2 cm in length.
3. Always use numerals with the abbreviated unit and use abbreviated units wherever possible – in lists of statistics, in tables and line artwork.
4. Numeral and units should be separated by a thin space, i.e. 100 km, not 100km (this does not need to be indicated by the CE, the TS will format, PR/PE to check). NOTE: exception to the thin space rule applies for percent and degree symbols, i.e. 90% and 35.7°
5. Abbreviations of units are the same for singular and plural (do not add an s); they do not take a full point. E.g. 25 min, 55 s
6. Use SI units wherever possible (see specific Journal webpages for more specific notes).

Numbers

1. Spell out numbers one to nine; for numbers 10 and over use numerals, except at the beginning of a sentence. Re-work the sentence if necessary.
2. Use numerals with percentages (use the % symbol, not per cent or percent), with units, in statistical passages, in tables, etc.
3. Spell out and hyphenate one-half, two-thirds, etc.
4. Do not use a comma in 4-digit numbers (thousands) but do use one in 5-digit numbers (tens of thousands) and above, e.g. 5643; 1298; 14,600; 342,685; 1,000,001. Do *not* use a thin space.
5. Do not contract number ranges, e.g. page ranges and dates; i.e. use pp. 24–29, 13–15 October, 1981–1999 etc.
6. Decimal points are never raised off the line.
7. Do not mix spelled-out numerals and units: 6 cm not six cm.

Dates

1. Write out dates in text and refs as follows: 30 September 2003, except in Tables if space is short, then a shortened version may be used, e.g. 11 Sep 08 (do not use 11/9/08, as this could be confused in the US as 9th November).
2. Do not use an inverted comma in decades, e.g. 1960s, mid-1930s. Avoid 80s, etc.
3. Use numerals for centuries (except in history journals where it is spelled out), e.g. a 21st-century dilemma.

4.4 Abbreviations
General

1. Do not use abbreviations in the title of a paper, in the abstract, or keywords, unless the full version is very long and clumsy or the abbreviation is better known than the full term (e.g. DNA). Abbreviations may be used in headings and subheadings if they has already been defined previously in the paper at first usage. If in doubt, spell out.
2. Define an abbreviation the first time that it is used (except in the Abstract): write the term out in full followed by the abbreviation in parentheses. Use the abbreviation consistently thereafter, including at the start of sentences.
3. For plural terms, use plural abbreviations, e.g. low-density lipoprotein, LDL; low-density lipoproteins, LDLs.
4. If you need to abbreviate months or days of the week (for example, in a crowded table), use the first three letters without a full-stop (Mon, Tue; Jan, Feb).

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5. If abbreviations are used in a figure or table, they must all be defined in the caption or in a Table note/footnote even if they are also defined in the text.
6. Do not use abbreviations invented by the author of a paper for that paper – ideally, only conventional, generally accepted abbreviations should be used.
7. Do not abbreviate single words (exceptions apply) or use two-letter abbreviations other than those listed below. (Two-letter engineering abbreviations are available in the IMechE Style Guide supplement).
8. Abbreviations consisting of capital letters, and acronyms and contractions, should not take full points, e.g. USA, UK, MA, UN, WHO, PhD, NATO (or Nato), UNESCO (or Unesco), AD, BC
9. Unfamiliar (but generally accepted) abbreviations should always be written out in full when first mentioned, with the abbreviated form following in parentheses, e.g. "The Confederación Española de Derechas Autónomas (CEDA) was formed". Thereafter use the abbreviation.
10. Contractions do *not* take a full point, e.g. Mr, St, Ltd, edn, Dr, neither do contracting degrees (Dr, DPhil, PhD, MSc). The following abbreviations take full points: no., Co., p., pp., vol., ch. (but use vols and chs), e.g., ed. (but use eds), et al., etc., i.e., cf., (note that this means 'compare' and not 'see'), n.d.
11. No comma after e.g., i.e. or cf. Etc. has a full stop and is usually preceded by a comma in a list. They may be used in lists or figure or table legends, and within parentheses.
12. In reference lists, notes, footnotes, corresponding author address (if required) and authors' biographical notes, please use the standard abbreviated form for American states (and Canadian/Australian territories). Please spell out in full in the text (see section 7.3 for full list of US state abbreviations).

Some journals use abbreviations that do not need to be spelled out, even at first usage. For a full list of abbreviations that do not need to spelled out for each individual journal, please visit the journal webpage.

STM abbreviations: some abbreviations of terms that we do not define in full are listed here (follow style given):

- SD = standard deviation
- SEM = standard error of the mean
- NS = not significant
- a.m. in the morning (but use 24-hour clock if possible)
- p.m. in the afternoon
- N/A = not applicable
- Chemical symbols (H_2O, H_2SO_4) may be used without definition. However, write in full unless this is inappropriate (e.g. 'Water consists of hydrogen and oxygen'; 'Nitric oxide is also found in peripheral nerves'). Refer to *Scientific terminology* notes for further guidance.

See the Appendix (pp. 26 and 27) for a full list of accepted general two-letter STM abbreviations and engineering abbreviations.

5. Technical content: maths, equations, etc.

5.1 Maths notation convention

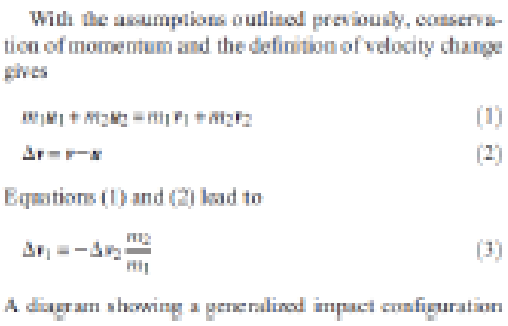
There is no specific convention for mathematical notation in terms of matrices, vectors, variables, operators, functions, subscripts, superscripts and scalars. CE please follow the author's symbols and notation conventions, ensuring that these are consistent throughout the paper.

Please query the author if any symbols are unclear, duplicated with more than one definition, or undefined.

5.2 Equations

Layout of equations

1. Equations should be left aligned on a 3 mm indent, *not* centred.
2. Equations should be numbered in sequence throughout the text, with the numbering continuing through all appendices. However, equations only need to be numbered if cited in the text, and not all equations necessarily need to be numbered.
3. Equation numbers should be set flush right and in sequence. Each numbered equation should have its own line.
4. No punctuation is used before or after an equation (i.e. no commas, colons, hyphens etc.)
5. The equation number should align with the *bottom line of* equation. Where the equation number covers multiple equations, it should align with the bottom line of the last equation.
6. When referred to in text, equations take the form 'equation (1)'. When a range of equation numbers is referred to, use the form: equations (1) and (2); equations (1) to (3); equations, (1), (2), and (5) to (7).



With the assumptions outlined previously, conservation of momentum and the definition of velocity change gives

$$m_1 u_1 + m_2 u_2 = m_1 v_1 + m_2 v_2 \quad (1)$$

$$\Delta v = v - u \quad (2)$$

Equations (1) and (2) lead to

$$\Delta v_1 = -\Delta v_2 \frac{m_2}{m_1} \quad (3)$$

A diagram showing a generalized impact configuration

7. If two or more small equations or conditions can fit on one line, then they should be well separated with a 2-em space. Commas and words, set upright not italic, may be used to enhance clarity.
8. Equations in text must be reduced to one line depth. Display equations are built up to two line depth. For instance, the equation $(x - y)/(x^3 + 2y - 3)$ runs on in the text but for display becomes
$$\frac{x - y}{x^3 + 2y - 3}$$
9. CEs: Spaces between + and – and other operators need not be marked. TS will format.
10. Unless separating small equations and conditions, as shown above, odd words between equations such as 'where', 'and', 'thus', 'therefore' should be on a separate line from the equations and flush left. Only use initial capitals for these if they start a new sentence.
11. When a single equation has been presented with a label/header (e.g. 'momentum conservation equation', 'blade element momentum theory', etc.), present the label before the equation, full left, half-line above, and in roman.
12. Where an equation is too long to fit on one line, take over whole terms starting if possible with a + or – or = symbol, and indent.
13. Where a bracketed term has to be split over lines move the second part to the right to show it is still part of the same term (align to the right of the bracket).
14. Pairs of opening and closing brackets should be the same size, even when they are on different lines.
15. Where an equation breaks at an equals sign indent a further em in from the first line.
16. Where equations are split over 2 lines, the break should occur before the operator.

$$m_2(1+e_y)(U_{2y}-U_{1y})$$
$$=(m_1+m_2)\Delta v_1-m_1h_1\Delta\omega_1-m_2h_2\Delta\omega_2 \qquad (9)$$

5.3 Units

SI preferred. Expressions such as rpm, psi, cfm, gpm, mph, kph, tsi, revs should be avoided. Use instead r/min, lbf/in^2, gal/min, mile/h, km/h, ton/in^2, rotational speed, etc.

Notes: Greek μ in μm should always be roman; MPa and GPa should always have a capital P.

5.4 Symbols and operators

A thin non-breaking space should separate symbols and operators from numerals, and be present either side of multiplication dots and all operators, e.g. +, -, =, x, <, >, etc. (this does not need to be indicated by the CE, the TS will format)

Appendices and notation (see section 2.6, p. 7)

6. Appendices

6.1 General STM acceptable 2-letter abbreviations *(should be defined on first mention)*:

AH	arterial hypertension	ML	maximum lysis
AP	anteroposterior	MR	magnetic resonance
AR	androgen-receptor	MS	multiple sclerosis
AS	ankylosing spondylitis	ND	no data
AT	anti-thrombin	NF	nuclear factor
BP	blood pressure	NK	natural killer
CE	centre–edge	OD	optical density
CF	cystic fibrosis	OR	odds ratio
CI	cardiac index	OS	overall survival
CI	confidence interval	PC	protein C
CO	cardiac output	PD	potential difference
CP	cerebral palsy	PD	progressive disease
CR	complete response	PE	probable error
CT	clotting time	PP	pulse pressure
CT	computed tomography	PR	partial response
ED	emergency department	PT	prothrombin time
ED50	median effective dose	RA	rheumatoid arthritis
EU	European Union	RA	right atrium
FA	fatty acid	Rh	rhesus
FA	folinic acid	RQ	respiratory quotient
FR	fixed ratio	RR	relative risk
GH	growth hormone	RR	response rates
GM	genetically modified	RT	room temperature
GP	general practitioner	RV	right ventricle
Hb	haemoglobin	SE	standard error
HR	heart rate	SV	stroke volume
IR	Infrared	TB	tuberculosis
LD50	median lethal dose	TC	total cholesterol
LH	luteinising hormone	TF	tissue factor
LV	left ventricle	TS	thymidylate synthase
mAb	monoclonal antibody	TT	thrombin time
ME	medial epicondyle	UV	ultraviolet
ME	myalgic encephalomyelitis	VD	venereal disease
MI	myocardial infarction		

***6.2 Engineering acceptable 2-letter abbreviations** (should be defined on first mention):*

AC/DC	alternating current/direct current	HC	hydrocarbon
A/C	air conditioning	KF	Kalman filter
AI	artificial intelligence	MR	magnetorheological
AI	auto-ignition	MR	magnetic resonance
CA	crank angle (also used as a unit of measurement)	MS	mass spectrometry
CC	combustion chamber	MW	molecular weight
CG	centre of gravity	NN	neural network
CI	compression ignition	NS	Navier–Stokes
CM	centre of mass	PI	proportional–integral
CV	cyclic variability	PM	particulate matter
DI	direct injection	*Re*	Reynold's number
EA	evolutionary algorithm	RF	radio frequency
EM	electromagnetic	RI	rollover index
EV	electric vehicle	SD	standard deviation
FE	finite element	SI	spark ignition
GA	genetic algorithm	TC	traction control
GT	gas turbine	UV	ultraviolet

6.1 SAGE Harvard

1. General

1. Initials should be used without spaces or full points.
2. Up to three authors may be listed. If more are provided, then list the first three authors and represent the rest by et al. Fewer authors followed by et al. is also acceptable.

2. Text citations

1. All references in the text and notes must be specified by the authors' last names and date of publication together with page numbers if given.
2. Do not use ibid., op. cit., infra., supra. Instead, show the subsequent citation of the same source in the same way as the first.
3. Where et al. is used in textual citations, this should always be upright, not italic.

Note the following for the style of text citations:

1. If the author's name is in the text, follow with year in parentheses:

... Author Last Name (year) has argued ...

2. If author's name is not in the text, insert last name, comma and year:

... several works (Author Last Name, year) have described ...

3. Where appropriate, the page number follows the year, separated by a colon:

... it has been noted (Author Last Name, year: page nos) that ...

4. Where there are two authors, give both names, joined by 'and'; if three or more authors, use et al.:

... it has been stated (Author Last Name and Author Last Name, year) ... ... some investigators (Author Last Name et al., year) ...

5. If there is more than one reference to the same author and year, insert a, b, etc. in both the text and the list:

... it was described (Author Last Name, yeara, yearb) ...

6. Enclose within a single pair of parentheses a series of references, separated by semicolons:

... and it has been noted (Author Last Name and Author Last Name, year; Author Last Name and Author Last Name, year; Author Last Name, year) ...

Please order alphabetically by author names.

7. If two or more references by the same author are cited together, separate the dates with a comma:

... the author has stated this in several studies (Author Last Name, year, year, year, year) ...

Please start with the oldest publication.

8. Enclose within the parentheses any brief phrase associated with the reference:

... several investigators have claimed this (but see Author Last Name, year: page nos–page nos)

9. For an institutional authorship, supply the minimum citation from the beginning of the complete reference:

... a recent statement (Name of Institution, year: page nos) ... ... occupational data (Name of Bureau or Institution, year: page nos) reveal ...

10. For authorless articles or studies, use the name of the magazine, journal, newspaper or sponsoring organization, and not the title of the article:

... it was stated (*Name of Journal*, year) that ...

11. Citations from personal communications are not included in the reference list:

... has been hypothesized (Name of Person Cited, year, personal communication).

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3. Reference list

1. Check that the list is in alphabetical order (treat Mc as Mac).
2. Names should be in upper and lower case.
3. Where several references have the same author(s), do not use ditto marks or em dashes; the name must be repeated each time.
4. Last Names containing de, van, von, De, Van, Von, de la, etc. should be listed under D and V respectively. List them as: De Roux DP and not Roux DP, de. When cited in the main text without the first name, use capitals for De, Van, Von, De la, etc. (Van Dijk, year)
5. Names containing Jr or II should be listed as follows:
   - Author Last Name Initial Jr (year)
   - Author Last Name Initial II (year)
6. References where the first-named author is the same should be listed as follows:
   - Single-author references in date order;
   - Two-author references in alphabetical order according to the second author's name;
   - Et al. references in alphabetical order; in the event of more than one entry having the same date, they should be placed in alphabetical order of second (or third) author, and a, b, etc. must be inserted.

   Brown J (2003)
   Brown TR and Yates P (2003)
   Brown W (2002)
   Brown W (2003a)
   Brown W (2003b)
   Brown W and Jones M (2003)
   Brown W and Peters P (2003)
   Brown W, Hughes J and Kent T (2003a)
   Brown W, Kent T and Lewis S (2003b)
7. Check that all periodical data are included – volume, issue and page numbers, publisher, place of publication, etc.
8. Journal titles should not be abbreviated in SAGE Harvard journal references
9. Where et al. is used in reference lists, it should always be upright, not italic.

4. Reference styles

Book

Clark JM and Hockey L (1979) *Research for Nursing*. Leeds: Dobson Publishers.

Book chapter

Gumley V (1988) Skin cancers. In: Tschudin V and Brown EB (eds) *Nursing the Patient with Cancer*. London: Hall House, pp.26–52.

Journal article

Huth EJ, King K and Lock S (1988) Uniform requirements for manuscripts submitted to biomedical journals. *British Medical Journal* 296(4): 401–405.

Journal article published ahead of print

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Abstract

This systematic literature review updated the current child and adolescent literature exploring potential gender differences between males and females aged 0–18 years old with Autism Spectrum Disorder (ASD). The outcomes of 17 papers dated 2013–2015 were synthesised into seven themes concerning the areas under investigation: neurobiological abnormalities (n = 2); co-morbidity and problematic behaviours (n = 4); cognitive functioning (n = 4); core ASD symptomatology (n = 4); ASD risk factors (n = 1); age at diagnosis (n = 1); access to services and parental distress (n = 1). Although mixed, the results tentatively indicated that boys and girls with ASD are more similar than different in the severity of their core ASD symptomatology, yet differ with regards to: neurobiological abnormalities; sensory sensitivity; the quality and nature of repetitive and restrictive behaviours, interests and activities; the co-morbidity of other conditions; and parental distress levels. The limitations of this review and accompanying clinical and research implications are discussed.

Keywords

Autism Spectrum Disorder, gender differences, children, adolescents

Introduction

Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental disorder that influences how an individual communicates with and understands others in social situations (The National Autistic Society; NAS, 2015). ASD influences behaviour in the form of repetitive and restrictive behaviours, interests and activities (NAS, 2015). ASD is recognized as a neurodevelopmental disorder in the *International Classification of Diseases* (*ICD–10*; World Health Organisation; WHO, 2015) and the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; *DSM–5*; APA, 2013). Recent changes in the *DSM-5* have defined ASD as being along continuums of severity and the level of support the individual requires in their daily lives (APA, 2013).

There is ongoing interest within the ASD research field regarding potential gender differences between males and females with ASD (e.g. Dworzynski et al., 2012; Ehlers and Gillberg, 1993; Gould and Ashton-Smith, 2011; Knickmeyer et al., 2008; Wing, 1981a). Gender is defined as a '…psycho-social construct expressed through particular behaviours consistent with socio-cultural expectations derived from…genetic sex' (Goldman, 2013: 675).

Previous reviews of the literature exploring potential gender differences have looked at data across all age cohorts (Kirkovski et al., 2013; Lai et al., 2015; Rivet and Matson, 2011; Rubenstein et al., 2015; Schaafsma and Pfaff, 2014; Van Wijngaarden-Cremers et al., 2014; Werling and Geschwind, 2013). There are pros and cons to this approach, but a dearth of child and adolescent-specific reviews could lead to a lack of easily accessible reference material for parents and professionals. The aim of this review was to provide an update on the research on the potential gender differences between

males and females with ASD aged up to eighteen years. This will be accomplished by qualitatively synthesising the current literature not yet evaluated.

What do we know so far?

Findings from the aforementioned reviews (see Table 1; Supplemental File A) suggest that children with ASD present with atypical brain growth in early infancy (Courchesne et al., 2001; Nordahl et al., 2011; Whitehouse et al., 2011), with females reportedly experiencing more severe, globalised abnormalities (Bloss and Courchesne, 2007; Nordahl et al., 2007; Schumann et al., 2009). The proposed gender ratio of four males to every one female reportedly narrows with reduced intellectual ability to 2:1 respectively (Fombonne, 2005; Hartley and Sikora, 2009; Wing, 1981b).

Gender differences in ASD are purportedly mediated by certain pre-, peri- and post-natal factors (Abrahams and Geschwind, 2008; Patterson, 2009; Pfaff et al., 2011). For example, pre-natal gonadal hormones (Hampson et al., 1998; Hines et al., 2003; Knickmeyer et al., 2005), maternal immune activation (e.g. Lenz et al., 2013; Parker-Athill and Tan, 2010; Theoharides et al., 2011), and pre-natal stress (e.g. Emack and Matthews, 2010; Mueller and Bale, 2007) proposedly affect the male and female foetus differently, potentially influencing the gender-specific etiology of ASD. Schaafsma and Pfaff (2014) conclude that birth related variables commonly associated with gender differences in ASD include genetic mutations, hormonal imbalances (i.e. high testosterone levels), environmental stressors and the child's gender itself. Some scientists propose that females need to be exposed to higher levels of ASD risk factors (i.e. a higher burden of genetic mutations) than males, in order to develop ASD (Iossifov et al., 2014;

Sanders et al., 2011), aptly named the 'Female Protective Effect' (FPE) (Jacquemont et al., 2014; Robinson et al., 2013).

There is additional evidence suggesting that females with ASD may present with fewer social skills deficits and behaviours that challenge others (McLennan et al., 1993), fewer repetitive and restrictive behaviours, interests and activities (Bölte et al., 2011; Carter et al., 2007; Hartley and Sikora, 2009; Hattier et al., 2011; Lai et al., 2011; Szatmari et al., 2012) and more internalised behavioural difficulties (Mandy et al., 2012; Matson and Love, 1990), than males with ASD.

Despite the proposed variations outlined so far, other literature conversely suggests that there are fewer differences between males and females than there are similarities (e.g. Holtmann et al., 2007; Horovitz et al., 2012; Pilowsky et al., 1998), particularly with regards to the severity of core ASD symptomatology as specified in the *DSM-5* (APA, 2013) and *ICD-10* (WHO, 2015). This view has been echoed by Lai et al. (2015) who states that males and females with ASD and average or above intelligence are alike with regards to their core ASD symptomatology. For the purposes of this review core ASD symptomatology is defined as '…qualitative impairments in social interaction and communication, and restricted, repetitive, and stereotyped patterns of behavior, interest, or activities' (Rivet and Matson, 2011: 959)

Evidently, outcomes within the ASD gender literature are mixed. This may in part be due to variations in study design, methodology, global location, and the neuro-developmental or psychometric measures used. For example, few studies within the literature have compared males and females with ASD to males and females without ASD, creating uncertainty as to whether the gender outcomes are ASD-specific, or rather

akin to globalised gender differences seen in the general population. It is also plausible that social expectations regarding boys' and girls' behaviour allow similar ASD symptoms and presentations to be viewed differently, with potentially more boys being identified earlier than girls. Other common limitations within the ASD gender literature include small sample sizes, unbalanced gender representations, and poor generalisability of findings.

Despite the complexities associated with drawing a shared understanding, the topic of gender differences in ASD continues to stimulate extensive research. This systematic review attempts to update what is known so far by qualitatively synthesising the current ASD gender literature yet to be reviewed, with a narrowed focus on the younger generation aged 0–18 years old. Reference will be made to whether the aforementioned limitations noted by previous reviews are still influencing the evidence base and consequently the professional and personal utility of their findings.

Method

Inclusion/ exclusion criteria

Included studies were in the English language, with participant samples aged 0–18 years old with an ASD diagnosis, where gender comparisons were made. Studies were excluded if participants were aged over 18 years old, did not have an ASD diagnosis, and if no gender comparisons were made. Books, editorials, case reports, dissertations and commentaries were also excluded.

Search criteria

The review began by systematically checking published peer-reviewed journal articles dated January 1980 to June 2015, as listed in the electronic databases SAGE

journals, PubMed, Web of Science and Science Direct. The specific search terms used consisted of the following combinations: *"sex OR male OR female OR gender AND difference* AND children OR youth OR child* OR adolescent* AND autism OR autism spectrum disorder OR ASD OR autistic*"*. Following database searches, a hand search of references from the aforementioned seven review papers and an online search using the Google Scholar search engine, were conducted.

Search outcome

Following the initial screening of titles, abstracts and keywords, 104 records were read in full and assessed for eligibility (see Fig. 1; Appendix A). Of these full text articles, 31 did not meet the inclusion/ exclusion criteria, and 56 had already been included in previous reviews. Seventeen studies were selected for review, consisting of peer-reviewed journal articles published between 2013 and June 2015.

Place Fig. 1 here

Results

Article characteristics

Nine studies were conducted in the USA, one in Australia, two in Israel, and one each from Canada, Singapore, Japan, Italy and Iran. With regards to study design, 14 of the 17 studies included for review were quasi-experimental and three were cohort studies. Only five studies included a typically developing (TD) control group for comparison. Seven studies recruited individuals with average or above intellectual ability; five recruited mixed samples with below, average, or above average intellectual ability; one study recruited individuals of below average intellectual ability; and four did not assess

for this. The number of girls recruited into the studies ranged from 11 to 336. For boys it was considerably higher, ranging from 26 to 1495. Overall sample sizes ranged from 46 to 2418 (Table 2; Supplemental File B).

Themes

To coherently present the findings of this review, seven themes are proposed in accordance with the area of ASD gender differences under investigation: neurobiological abnormalities (n = 2); co-morbidity and problematic behaviours (n = 4); cognitive functioning (n = 4); core ASD symptomatology (n = 4); ASD risk factors (n = 1); age at diagnosis (n = 1); and access to services and parental distress (n = 1) (Table 2; Supplemental File B).

Neurobiological abnormalities

Abnormal brain connectivity and abnormal white matter development has been identified in individuals with ASD (Bakhtiari et al., 2012; Delmonte et al., 2013; Vissers et al., 2012). Nordahl et al. (2015) and Sussman et al. (2015) highlighted possible neurobiological gender differences between boys and girls with ASD, using imaging technology techniques such as structural magnetic resonance imaging (MRI).

Nordahl et al. (2015) compared the corpus callosi of 139 pre-school children with ASD and 82 TD controls aged 3–5 years old using an application of MRI, to explore possible ASD gender differences in corpus callosum abnormality. Mixed-effects regression models suggested that boys (n = 112) and girls (n = 27) with ASD both had smaller callosal regions which project to the superior frontal cortex, compared to TD controls. However, they significantly differed in the diffusivity of calossal fibers and the

patterns of callosal sub regions, which project to other regions of the frontal cortex. Such abnormalities and gender differences were reportedly present by three years of age.

In further detail, the diffusivity of callosal fibers was significantly increased in girls with ASD compared to boys with ASD ($p < 0.02$), and boys with ASD had a significantly smaller orbitofrontal fibre region compared to TD males (estimated difference = -6.98, $p = 0.02$) and girls with ASD (estimated difference = -8.66, $p = 0.02$). Such neurobiological abnormalities could potentially influence the emotional processing and decision-making abilities of young boys with ASD. Interestingly, girls with ASD had a significantly smaller anterior frontal fibre region compared to TD females (estimated difference = -20.45, $p = 0.01$) and boys with ASD (estimated difference = 16.77, $p = 0.01$). Such abnormalities could influence executive functioning and other cognitive abilities. Girls with ASD also had a smaller posterior parietal fibre region compared to TD females (estimated difference = -13.34, $p = 0.07$) and boys with ASD (estimated difference = 15.75, $p = 0.01$). The gender similarities and differences found in the ASD group were not found in the TD control group.

In summary, ASD gender differences in calossal organisation may lead to differing ASD liability thresholds for males and females, with girls only being diagnosed with autism if the severity of their condition is more serious, whereby any neural markers of ASD are more likely to be bigger (Nordahl et al., 2015).

Moving on, Sussman et al. (2015) highlighted various atypical changes occurring in the brain with age (4–18 years) for 72 boys and girls with ASD, as compared to 138 TD gender and age matched controls. Children in the ASD group reportedly showed early brain overgrowth peaking at 11 years of age and decreasing from 12 years, with a smaller

average hippocampal volume than that of matched controls. Boys and girls with ASD were also shown to have reduced volume of the globus pallidus and thalamus, compared to controls. Boys with ASD (n = 61) were shown to have larger total cerebral volume, as compared to girls with ASD (n = 11) and TD males (n = 116). Interestingly, no significant differences were found with regards to surface area and cortical volume between girls with ASD and TD female controls (n = 22), yet girls with ASD were shown to have smaller relative volume of the hippocampi than boys with ASD and TD female controls. It is possible that the observed neurobiological differences in hippocampal and cerebellar volume may lead to ASD-specific gender differences in sensory processing, motor, and verbal memory abilities. This is an important consideration for future research exploring the functional consequences of such neurobiological differences, particularly in light of the significant volumetric differences reported in boys with ASD.

In light of the above findings, differing diagnostic practices may be required for boys and girls, as well as incorporating neuropsychological assessment and the use of brain imaging technology into future investigations.

Co-morbidity & problematic behaviours

Four research teams have recently explored whether ASD gender differences exist for young individuals with ASD in the additional presence of co-morbid conditions and problematic behaviours that challenge others (Baker and Milivojevich, 2013; Hill et al., 2014; Magiati et al., 2015; Stacy et al., 2013).

Baker and Milivojevich (2013) used an online medical database (i.e. Autism360), to gather parental reports on the strengths and symptoms of boys (n = 1495) and girls (n = 336) with ASD aged 2–18 years old. The girls were reportedly experiencing significantly

more co-morbid functional disturbances than boys in the form of immune tolerance and gastrointestinal problems such as constipation, and allergic reactions to certain foods and pets. The girls also reportedly experienced more developmental delay. In comparison the boys were reportedly experiencing higher activity levels and behavioural difficulties seen in the form of more destructive or inappropriate and repetitive behaviours and rectal digging, 'stimming' and fidgeting behaviours.

In light of the fewer parental reports from parents of girls, and alongside a previous suggestion that females may have a more passive or internalised presentation (Werling and Geschwind, 2013), it is plausible that fewer parents of girls felt the need to report on their child's tendencies if they were not overly challenging or noticeable to others.

Using the Spence Children's Anxiety Scale-Parent version (SCAS-P; Spence, 1999), Magiati et al. (2015) found no significant association between gender and co-morbid anxiety symptoms or subtypes, in 197 boys and 44 girls with ASD aged 6–18 years old from Singapore. Although the SCAS-P is a validated measure for assessing anxiety in children, the authors duly commented that the validity and reliability of the SCAS-P with children with ASD was unknown at this time.

Stacy et al. (2013) explored possible gender differences between 913 boys and girls with ASD aged 3–17 years old for nine co-occurring conditions: attention deficit hyperactive disorder (ADHD); intellectual disability; developmental delay; speech difficulties; anxiety; depression; behavioural/conduct issues; seizures/epilepsy; and hearing difficulties. Data was obtained from parent reports through the 2007 National Survey of Children's Health (Blumberg et al., 2012).

Intriguingly, the girls were almost eight times more likely to be diagnosed with speech difficulties (OR = 7.85; 95% CI = 2.63–23.46), and less likely to present with a mild intellectual disability (OR = 0.18; 95% CI = 0.06–0.51), or two or more co-morbid conditions (OR = 0.28; 95% CI = 0.08–0.97) than the boys. Girls previously diagnosed with speech difficulties were likely to lose this diagnosis if diagnosed with ASD later on in childhood and African-American girls were three and a half times more likely to be diagnosed with ASD than African-American boys (OR = 3.49; 95% CI = 1.12–10.89). Unlike Baker and Milivojevich (2013), no gender differences were found between boys and girls with ASD in the prevalence of co-occurring behavioural/conduct problems, ADHD or epilepsy.

Aggressive behaviour is sometimes reported by parents of children and adolescents with ASD (Carroll et al., 2014; Lecavalier et al., 2006), yet there is no strong evidence to date that aggression is associated with or influenced by gender (Kozlowski and Matson, 2012; Mazurek et al., 2013; Murphy et al., 2009). Hill et al. (2014) investigated the relationship between aggressive problem behaviors and specific demographic factors (i.e. gender) in 400 children aged 2–16.9 years old with ASD. Aggressive problem behaviors were measured using the Child Behaviour Checklist (CBCL; Achenbach and Rescorla, 2000) which assesses for verbal and physical aggression, mood changes, temper tantrums and property destruction. Sociodemographic factors purportedly unrelated to aggressive problem behaviours included gender, race, ethnicity, and level of caregiver education.

Cognitive functioning

The relationship between gender and the cognitive profiles of individuals with ASD has been explored with somewhat inconsistent results (Craig et al., 2007; Freeman et al., 1985; Lai et al., 2011). Kumazaki et al. (2015) recently examined the interaction between gender and the cognitive and ASD symptom profiles of 46 children aged 5–9 years old with ASD, with average or above intelligence. Measures used included the Japanese version of the Wechsler Intelligence Scale for Children-Third edition (WISC-III; Wechsler, 1991) and the Childhood Autism Rating Scale-Tokyo version (CARS-TV; Kurita et al., 1989). No significant gender differences were found between boys (n = 26) and girls (n = 20) with ASD in their verbal, performance, or overall intelligence scores on the WISC-III. However, it is important to note that the boys performed more poorly on the coding subtest of the assessment compared to girls, as evidenced by a medium effect approaching significance (d = 0.53, p = 0.07).

No gender differences were found for age at diagnosis, ASD symptom profile and condition severity. When looking at individual items on the CARS-TV, some significant gender differences were found. The boys presented with significantly higher levels of abnormal body (F(1,43) = 5.03, p = 0.03) and object use (F(1,43) = 13.27, p = 0.01) and activity levels (F(1,43) = 5.35, p = 0.02), than the girls. The girls presented with significantly higher levels of abnormal sensory sensitivity to smells, touch and taste (F(1,43) = 8.04, p = 0.03). To assess the external validity and generalisability of the above findings it would be useful to replicate this study across other countries with a more sophisticated measure than the CARS-TV and a larger sample size.

Even though the former study did not support gender variation on the WISC-III, Memari and colleagues (2013) suggested that gender *is* significantly associated with cognitive flexibility performance, as measured by the Wisconsin Card Sorting Test (WCST; Grant and Berg, 1948). Their sample consisted of 94 boys and 29 girls (n = 123) aged 7–14 years old with ASD with average or above intelligence. Overall, boys performed significantly better than girls on a measure of cognitive flexibility, whereby the girls made more errors due to perseveration ($F(1120) = 6.44$, $p = 0.012$) and completed fewer categories ($F(1120) = 10.11$, $p = 0.002$). Curiously, performance on the WCST was inversely associated with appropriate daily social play ($r = - 0.31$, $p = 0.001$), although this negative linear relationship was relatively weak. Memari et al. (2013) propose that such gender differences in cognitive flexibility may lead to differences in how boys and girls with ASD present, due to the potential for differing cognitive or neurobehavioural phenotypes.

Messinger et al. (2015) argue that the gender differences in cognitive functioning previously found in young individuals with ASD are not ASD-specific and rather due to normative gender differences. Their study recruited a large sample of siblings of children with or without ASD, aged 0–1.5 years. Following an Autism Diagnostic Observation Schedule assessment (ADOS; Lord et al., 1989), the sample was split into three groups consisting of those who were viewed as ‘high risk’ with (1) or without (2) ASD who had a biological sibling with ASD, and those who were viewed as ‘low risk’ (3) without ASD and no biological sibling with ASD. The three groups were compared on their ADOS scores and cognitive functioning abilities, following administration of the Mullen Scales

of Early Learning (MSEL; Mullen, 1995) which assess fine motor, visual reception, expressive and receptive language functioning.

Irrespective of group association the girls' cognitive functioning abilities were significantly higher than the boys ($p < 0.001$), and no significant group by gender interactions were found for the ADOS or MSEL. Regardless of group, the boys presented with significantly higher levels of repetitive and restrictive behaviours than the girls ($d = 0.29$, $p < 0.05$). Nevertheless, the effect size was relatively small. It is possible that the observed gender differences in cognitive functioning were not necessarily ASD-specific and rather indicative of normative gender differences seen in the general population.

In support of the above findings, Ross et al. (2015) found that when comparing the multi-sensory speech processing abilities of boys and girls aged 5–17 years with ASD with average or above intelligence ($n = 73$) with TD controls ($n = 102$), girls performed significantly better than boys under audio-visual listening conditions, regardless of group membership. Girls with ASD were shown to be significantly better than boys with ASD at integrating audio and visual speech ($F(1,70) = 3.48$, $p = 0.03$), suggesting that girls with ASD might have better audio-visual speech perception abilities. Girls with ASD may be better than boys with ASD at processing multisensory information in noisy environments (e.g. a classroom), which could facilitate social communication abilities in similar contexts.

Core ASD symptomatology

This section will start with Harrop and colleagues (2015) who explored gender differences in social-communication and play skills between 40 girls and 40 boys aged 1.8–4.9 years old with ASD. After Bonferroni adjustment, no significant differences were

found between boys and girls for joint attention, play type or play complexity. In summary, boys and girls with ASD in this study were reportedly more alike than dissimilar in their social communication and play skills.

Hiller et al. (2015) found that girls aged 6–17 years old with ASD (n = 60) were over five times better than boys with ASD (n = 92) at complex imitation (OR = 5.84; 95% CI = 1.57– 20.10, p = 0.01) and playing games involving imitation (OR = 5.12; 95% CI = 1.30–18.57, p = 0.02). Girls were shown to be mimicking others in social situations as a social strategy, along with an unusually strong desire to fit in with others (OR = 6.50; 95% CI = 1.11–9.96, p = 0.03), which was seen across the age range. This strong desire to fit in echoes previous suggestions in the literature (Head et al., 2014) that higher scores for girls with ASD on measures such as the Friendship Questionnaire (Baron-Cohen and Wheelwright, 2003) may be linked to a socially motivated desire to fit in and have friends. In Hiller and colleagues' study boys were more likely to use withdrawal, passive observation or isolation as social strategies (OR = 1.86; 95% CI = 0.15–0.81, p = 0.01), and presented with below average vocabulary skills (OR = 1.02; 95% CI = 0.19–0.95, p = 0.04) (Hiller et al., 2015). Contrary to other findings, concerns regarding externalising behaviours pre-diagnosis were reported over twice as often for girls, than for boys (OR = 2.89; 95% CI = 1.24–6.71, p = 0.01)

The quality and nature of the restrictive and repetitive interests of boys and girls differed, with girls purportedly lacking interest in mechanical objects as seen in the boys (OR = 3.33; 95% CI = 2.90– 17.11, $p < 0.001$), instead preferring random objects or stereotypically female objects. Teachers were considerably less likely to report concerns if the child was a girl. Contrastingly, parents of girls were more likely to share concerns

before their child's diagnosis due to behaviours that challenged others. No significant gender differences were found for age of first concerns reported by caregivers pre-diagnosis or for age at diagnosis.

Conversely, Reinhardt et al. (2015) observed no overall significant gender differences between boys and girls with ASD aged 0–3 years old (n = 288) on measures of developmental functioning, early social communication and adaptive functioning, compared to TD controls (n = 223). No significant difference and a small effect size was found upon comparison of the severity of boys' and girls' ASD symptomatology, yet girls in the TD control group scored significantly higher on measures of early communication skills, than TD males ($F(1,92.95) = 7.82$, $p < 0.05$).

In support of Reinhardt et al. (2015) but in contrast to Hiller et al.'s (2015) findings, Postorino and colleagues (2015) found no significant differences between boys (n = 30) and girls (n = 30) with ASD aged 2–5.4 years old, in their ASD symptoms over time. No significant interactions were found between gender and time for predicting severity of ASD symptoms, development, parental stress, adaptive skills or child behaviour problems. However, it is interesting to note that the girls (d = 0.09) showed bigger improvements over time in their cognitive development than the boys (d = 0.02).

ASD risk factors

Previous studies have investigated possible pre-, peri-, and post-natal risk factors associated with ASD (Guinchat et al., 2012; Kogan et al., 2009; Ozonoff et al., 2011; Schaaf and Zoghbi, 2011). Zachor et al. (2013) investigated the interaction between specific ASD risk factors and gender in children with ASD. Risk factors explored included parental age, a history of ASD in the family, birth order, low birth weight,

prematurity, and gestational age. None of the selected risk factors significantly interacted with gender, and the male to female ratio was reportedly lower in families with more than one child with ASD. No gender differences were found for ASD symptomatology, cognitive functioning and adaptive functioning. In light of these outcomes and previous mixed findings, further research in this area is required.

Age at diagnosis

According to Mishaal et al. (2014), the average age range during which children tend to receive an ASD diagnosis is three to six years of age. There is evidence to suggest that an early ASD diagnosis can improve outcomes for some children (Itzchak and Zachor, 2011). Mishaal and colleagues (2014) explored whether certain child and familial variables (i.e. child gender) influenced the timing of a child's ASD diagnosis. Their sample consisted of 551 children aged six or below with ASD, with a male to female ratio of 6.8:1 respectively. No significant differences were found between boys and girls in the age at which they received their ASD diagnosis ($t(549) = 1.19$, $p > 0.05$), inferring in this instance that gender may not be an important variable in the timing of a diagnosis.

Access to services and parental distress

Previous findings highlight the negative impact that having a child or children with ASD can have on parental wellbeing (Dunn et al., 2001; Lecavalier et al., 2006; Tehee et al., 2009). The level of access to treatment services that a parent experiences has also previously been shown to have an impact on parental wellbeing and perceived stress levels (Johnson and Simpson, 2013; Renty and Roeyers, 2006). Only one study has recently explored the relationship between gender, level of access to treatment services,

and parental distress for parents of 166 young individuals aged 1–15 years old with ASD (Zamora et al., 2014).

Zamora and colleagues' (2014) results suggested no significant gender differences in the amount of services received, but that the child's gender significantly predicted the level of parental distress experienced ($p < 0.05$). Parents of girls with ASD reported experiencing more parental distress and dysfunctional interactions with their child, than parents of boys with ASD. Intriguingly, receiving less support from or reduced access to services was shown to increase stress levels for parents of girls only. Although the child sample was proportionately 78% male and all parents involved were female, the findings suggested that parents of girls in this sample were experiencing more stress and dysfunctional interactions with their child, and that being unable to access adequate support from services had a detrimental impact on their wellbeing.

Discussion

Summary of outcomes

Although boys and girls aged 0–18 years old appear to be more similar than they are different in the severity of their core ASD symptomatology, this review highlighted a number of potential differences in how boys and girls with ASD present. The tentative findings noted differing levels of sensory sensitivity (i.e. higher for girls; Kumazaki et al., 2015) and parental distress (i.e. higher for parents of girls; Zamora et al., 2014). Potential gender differences were also observed for the co-morbidity of other conditions (Baker and Milivojevich, 2013) and the quality and nature of repetitive and restrictive behaviours, interests and activities (Hiller et al., 2015). ASD-specific neurobiological differences between young male and female brains were noted, particularly in the

calossal region dedicated to the orbitofrontal cortex, the hippocampus and cerebellum (Nordahl et al., 2015; Sussman et al., 2015). Findings concerning cognitive functioning and externalising behaviours were mixed. As such, it is difficult to know whether the gender differences observed in the data were ASD-specific, or due to normative gender differences due to a lack of TD controls for comparison.

Based on the available evidence, it is also possible that girls may be using more active strategies than boys to manage social situations, such as mimicking (Hiller et al., 2015), supporting previous suggestions that girls with ASD have a strong desire for friendships (Head et al., 2014) and are able to mask their social skills difficulties in social situations (Attwood, 2000; Harrop et al., 2015; Wing, 1981a, 1981b). Gendered socialisation may play a role in this observation, whereby there may be higher expectations in certain cultures for girls to want to have friends and be sociable, to be 'chatty' and have sociable hobbies (Condry and Condry, 1976). Such findings may help to explain why the diagnostic process for some (but not all) girls can be delayed (Mishaal et al., 2014), rather than it necessarily being due to ASD unfolding more slowly in females (Reinhardt et al., 2015). The aforementioned findings may also help to explain conflicting adult reports on female behaviour across various social contexts, making it even harder for professionals to decide whether or not an ASD assessment for a young female is warranted.

Limitations & future research

Upon considering the possible limitations of this review, the first issue concerns the relatively small sample size compared to previous reviews. Another potential drawback relates to the narrative approach adopted, yet the authors felt that a meta-

analysis was inappropriate in this instance in light of the poor quality and heterogeneity of the final sample. Although the reviewed papers were highly varied with each theme covering a small number of papers, the overriding aim was to provide the most up to date information to inform understanding in a quickly evolving field for a variety of individuals supporting young people with autism.

It is prudent to point out that limitations and biases within the current sample are similar to those noted by the previous reviews (Kirkovski et al., 2013; Lai et al., 2015; Rivet and Matson, 2011; Rubenstein et al., 2015; Schaafsma and Pfaff, 2014; Van Wijngaarden-Cremers et al., 2014; Werling and Geschwind, 2013). The key weaknesses repeated in the reviewed literature included: not matching participants with TD controls; the use of unstandardised online questionnaires and/or retrospective parent reports and varying measures which may not be gender sensitive; the recruitment of small heterogeneous samples with unbalanced gender representations; poor generalisability to older or younger cohorts with differing intellectual abilities and cohorts from other cultures; no follow-ups; and the recruitment of participant samples from a single source (see Table 2, Supplemental File B for further details).

Undoubtedly, many researchers in the field face an uphill struggle trying to access a sufficiently large sample of female participants and also being able to ascertain whether the current ASD measures available (e.g. ADOS) are gender sensitive, or male biased. Where possible, future studies should attempt to include larger samples with equal numbers of boys and girls, matched with TD controls. Research might also benefit from incorporating more direct clinical observations into their methodology and from considering the influence of cultural and social expectations upon others' views of how

boys and girls should behave. More longitudinal studies are required which take into account changes in sex hormones with age and how this may influence outcomes. Studies could also look at the developmental trajectories of core ASD symptoms over time, with larger gender balanced and control-matched samples. Advances could facilitate earlier identification and enhance the interventions and support provided for young individuals with ASD and their caregivers.

Clinical implications

As stated at the outset, it is hoped that the present review provided an update on current findings regarding gender differences in young individuals with ASD, so as to inform professionals involved with service provision in this area.

Firstly, if young girls are being missed in the classroom setting (Hiller et al., 2015) and parents of girls are experiencing more parental distress and dysfunctional interaction with their child (Zamora et al., 2014), it highlights the need for teachers to be provided with adequate information about autism and the potential gender differences. This may help to improve the quality and timing of the assistance a young individual and their caregivers receive.

Secondly, increased attention needs to be given to the extent to which our own social and cultural expectations of boys' and girls' behaviours influence what we do or do not see in a young individual's presentation. Further awareness and training within primary and secondary care services, educational and local authority services, focused on sharing the current tentative findings within the ASD gender literature, could be helpful.

Thirdly, in light of the emerging consensus that girls with ASD may present with qualitatively different socially oriented behaviours and repetitive and restrictive

behaviours, interests and activities to boys with ASD, there needs to be further consideration into whether gender sensitive or specific assessment tools for ASD are required, and if so the funding and implementation implications of such changes. An alternative possibility is that the assessment tools do not necessarily need to be changed, yet the professionals carrying out the assessments must be aware of the current gender and ASD evidence base and the potential behavioural differences between boys and girls as suggested in the current and previous reviews. Considering the implications for assessment tools is important in light of the recent changes to the *DSM-5* criteria which require substantial evidence of repetitive and restrictive behaviours, interests and activities in an individual's presentation for a diagnosis of ASD to be considered. Concerns have been voiced that changes to the guidelines could unfairly disadvantage potentially autistic females (Wing, Gould and Gillberg, 2011).

Finally, such recommendations must be considered alongside the provision of higher quality research in order to further inform future clinical, professional and caregiving practices. This will be a vital yet challenging process.

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Note. * Studies included in review are marked with an asterisk

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Appendices

Appendix A

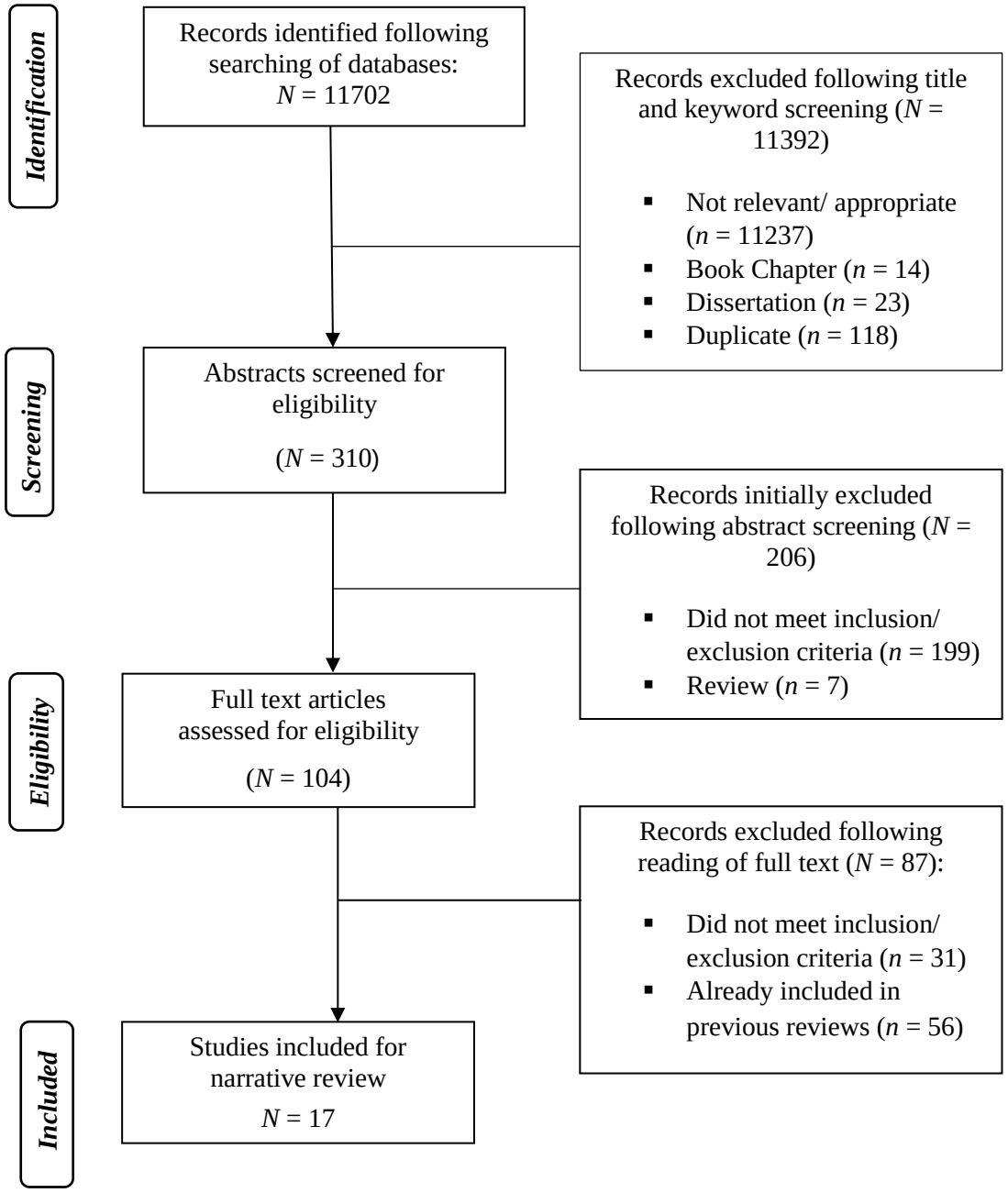

Figure 1. Flow diagram demonstrating selection procedure based on the Preferred Reporting Items for Systematic Reviews and Meta-analyses guidelines (PRISMA; Moher et al., 2009).

Supplemental Files

Supplemental File A

Table 1. The main findings of previous reviews.

Authors & *Date (most–least recent)*	**Area of Interest**	**Papers Reviewed *(n)***	**Publication Dates *(range)***	**Main Findings**
Lai et al. (2015)	Relationship between sex/gender differences and autism	329	1983 - 2014	• Females more likely to have intellectual and functional difficulties • Females present with fewer RRBIs than males • Neurological abnormalities more common in females • For high functioning individuals with ASD, females were 'different' in how they presented rather than being 'more severe' in their symptomatology • Potential for different gender 'subgroups' (i.e. phenotypes) in high functioning individuals
Rubenstein et al. (2015)	Gender differences in ASD phenotypes – developmental, medical, & psychiatric variables	69	1983 - 2013	▪ Repetitive and restrictive behaviours more common in males ▪ Intellectual disability more common in females ▪ Attention to detail may be more common in males ▪ Epilepsy may be more common in females ▪ No sex differences found for other developmental, medical or psychiatric symptoms ▪ Studies varied in their design, gender representation, sample sizes, methodology and global location – results inconsistent, less replicable and less externally valid to other cultures, populations, age ranges, etc.
Schaafsma and Pfaff (2014)	Genetic, epigenetic, hormonal, and environmental factors that may influence ASD gender differences and prevalence rates	N/S	N/S	▪ Maternal stress, inflammatory agents, high concentrations of endocrine disrupting chemicals in the environment and high levels of pre-natal gonadal hormones may affect baby boys and girls differently, leading to gender differences ▪ Boys are potentially more vulnerable to the above negative effects, thus increasing the prevalence of ASD in males ▪ Developed a '3 hit theory' – 1) numerous genetic mutations; 2) early environmental stressors and; 3) being male, all increase the risk of developing ASD

Authors & *Date (most–least recent)*	**Area of Interest**	**Papers Reviewed *(n)***	**Publication Dates *(range)***	**Main Findings**
Kirkovski et al. (2013)	Gender differences in ASD clinical presentation	113	1982 - 2012	▪ Age and cognitive ability were the two key mediating factors that influenced gender differences and symptomatology in ASD ▪ Gender differences in developing friendships, communicative ability and RRBI severity were inconclusive due to mixed and contradictory outcomes ▪ No gender differences in comorbid behavioural and mood psychopathologies ▪ Females may be more genetically protected from developing ASD than males due to genetic and prenatal differences ▪ Both genders present with atypical brain growth, but the changes occurring in the brain differ between the sexes
Van Wijngaarden-Cremers et al. (2013)	Gender differences in social and communicative behaviours and RRBI	22	1982 - 2012	▪ Females showed less severe symptoms of RRBI than males of the same age, from 6 years of age onwards. These differences were not seen in younger children ▪ No gender differences in social behaviour or communication ▪ Few gender differences in core ASD symptom severity ▪ Inconsistencies between studies in the ASD-specific measures used
Werling and Geschwind (2013)	ASD prevalence and gender differences in ASD phenotype	N/S	N/S	▪ ASD prevalence remains higher for males ▪ Fewer RRBI reported in females ▪ Fewer externalising behaviour problems reported in females ▪ Females are more protected from the effects of de novo and heritable ASD risk variants ▪ Boys are more at risk of developing ASD ▪ Testosterone shown to play a role in the sex differences in phenotypic presentation of ASD ▪ Females may show more socialising abilities than males ▪ Girls with autism may be more likely to act passively rather than act out when misbehaving than boys ▪ Girls may experience greater levels of anxiety, depression and emotional symptoms than boys
Rivet and Matson (2011)	Gender differences in	N/S	1971 - 2009	▪ Lower IQ scores have been found for females compared to males ▪ Gender ratio gap is less stark when intellectual disability is present

Authors & *Date (most–least recent)*	**Area of Interest**	**Papers Reviewed *(n)***	**Publication Dates *(range)***	**Main Findings**
	core ASD symptomatology			▪ Females may be less likely to manifest with the full range of ASD symptoms due to genetic or hormonal sex differences which may protect females ▪ Females report greater social skills difficulties in friendships ▪ Males showed greater social skills difficulties in displaying appropriate facial expressions ▪ Mixed findings on gender differences in socialization ▪ Higher epilepsy prevalence reported for females ▪ Girls tended to be diagnosed later in life than boys ▪ Females found to have higher thought and attention problems than males ▪ More internalised behaviour problems reported in females – anxiety, depression ▪ Girls more likely to be first born and from small families than boys ▪ More RRBIs reported in males than females ▪ More abnormal motor movements reported for females ▪ No significant differences found on ADI-R or ADOS overall scores, non-verbal social behaviours or reciprocal social interaction and relatedness ▪ Overall, few gender differences were found for ASD symptomatology ▪ Evidence of greater neurological impairment in females

ADI-R: Autism Diagnostic Interview-Revised; ADOS: Autism Diagnostic Observation Schedule; ASD: Autism Spectrum Disorder; IQ: Intelligence Quotient; N/S: Not Clearly Stated In Paper; RRBIs: Restrictive and Repetitive Stereotyped Behaviours, Interests and Activities.

Supplemental File B

Table 2. Study characteristics organised according to themes.

Theme	Authors *(Year; Location)*	Sample Sizes (*N*)		Age Range *(Years)*	Measures	Main Outcomes	Limitations/ Bias
		ASD Group *(n boys: n girls)*	Control Group *(n boys: n girls)*				
Neurobiological Abnormalities	Nordahl et al. (2015; USA)	139 (112:27)	82 (53:29)	3–5	▪ MRI ▪ ADOS-G ▪ MSEL ▪ ADI-R ▪ SCQ	▪ ASD gender differences observed in pattern of altered neuroanatomy in the corpus callosum, not seen in TD controls	▪ Small samples with fewer females ▪ Findings may not be generalisable to older cohorts ▪ Did not explicitly explore or discuss the functional consequences of differences in callosal organisation
	Sussman et al. (2015; Canada)	72 (61:11)	138 (116:22)	4–18	▪ MRI ▪ ADI-R ▪ ADOS-G	▪ Early brain overgrowth in ASD group ▪ Smaller hippocampi, thalamus and globus pallidus volume in ASD group ▪ Gender differences in hippocampus and cerebellum volume in ASD group only	▪ Small samples with fewer females ▪ Findings may not be generalisable to individuals with below average IQ
Co-Morbidity & Problematic Behaviours	Baker and Milivojevich (2013; USA)	1831 (1495:336)	N/A	2–18	Autism360 Online Database	▪ More cognitive, immune tolerance, central nervous system	▪ Fewer females in sample

Theme	Authors *(Year; Location)*	Sample Sizes (*N*) ASD Group *(n boys: n girls)*	Sample Sizes (*N*) Control Group *(n boys: n girls)*	Age Range *(Years)*	Measures	Main Outcomes	Limitations/ Bias
						and gastrointestinal problems prevalent in girls ▪ More behavioural abnormalities and increased activity prevalent in boys	▪ Retrospective and subjective parent reported data increased potential for recall bias ▪ No standardised measures used ▪ No direct observations across a variety of social contexts ▪ No TD control group for comparison – findings may not be ASD-specific
	Magiati et al. (2015; Singapore)	241 (197:44)	N/A	6–18	▪ SCAS-P ▪ DBC-P ▪ SIB-R ▪ Demographic Questionnaire	▪ No significant association between gender and prevalence of anxiety symptoms or anxiety subtypes as measured by SCAS-P ▪ No significant gender differences seen in DBC-P or SIB-R scores	▪ Small sample with fewer females ▪ Retrospective and subjective parent reported data increases potential for recall bias ▪ Mixed sample for intellectual ability ▪ No normative data for use of SCAS-P in Singapore – used Australian/ Dutch norms ▪ Low response rates on DBC

Theme	Authors *(Year; Location)*	Sample Sizes (*N*) ASD Group *(n boys: n girls)*	Sample Sizes (*N*) Control Group *(n boys: n girls)*	Age Range *(Years)*	Measures	Main Outcomes	Limitations/ Bias
							▪ No TD control group
	Stacy et al. (2013; USA)	913 (746:167)	N/A	3–17	National Survey of Children's Health (2007)	▪ Boys more likely to present with two or more co-morbid conditions than girls ▪ Boys currently more likely to have a mild intellectual disability than girls ▪ Girls more likely to be diagnosed with speech difficulties than boys ▪ African American girls 3.5 times more likely to be diagnosed with ASD, than African American boys	▪ Fewer females in sample ▪ Sampling of participant data from single source ▪ Co-morbid diagnoses reported in survey not verified by diagnosing clinicians ▪ Retrospective and subjective parent reported data increased potential for recall bias ▪ No other standardised measures used ▪ No TD control group
	Hill et al. (2014; USA)	400 (334:66)	N/A	2–16.9	▪ CBCL ▪ CSHQ ▪ Medical History Questionnaire	▪ Sociodemograhpic factors, including gender, unrelated to aggressive behaviour problems ▪ One in four children presented with co-morbid aggressive behaviour problems	▪ Fewer females in sample ▪ Missing data for measures (i.e. CSHQ) ▪ Mixed sample for intellectual ability ▪ Retrospective and subjective parent reported data increased potential for recall bias ▪ No TD control group

Theme	Authors *(Year; Location)*	Sample Sizes (*N*) ASD Group *(n boys: n girls)*	Sample Sizes (*N*) Control Group *(n boys: n girls)*	Age Range *(Years)*	Measures	Main Outcomes	Limitations/ Bias
Cognitive Functioning	Kumazaki et al. (2015; Japan)	46 (26:20)	N/A	5–9	▪ WISC-III ▪ CARS-TV (Japanese versions)	▪ No significant gender differences in age at diagnosis ▪ No significant gender differences found with WISC-III ▪ No significant gender differences in Total CARS-TV score ▪ Girls showed significantly less abnormal scores than boys on the 'Body Use', 'Object Use' and 'Activity Level' items of CARS-TV, yet significantly more abnormal scores on the 'Taste, Smell, Touch Response and Use' item	▪ Small sample recruited from single source ▪ Findings may not be generalisable to older cohorts ▪ Used a simplistic rating scale (CARS-TV) ▪ Findings may not be generalisable to younger individuals with below average IQ ▪ No TD control group
	Memari et al. (2013; Iran)	123 (94:29)	N/A	7–14	▪ WCST ▪ Activity Log ▪ ATEC	▪ Gender was strongly associated with cognitive flexibility performance on WCST whereby the boys performed significantly better than the girls ▪ Girls made more perseverative errors	▪ Small sample with fewer females ▪ Findings may not be generalisable to younger or older cohorts and individuals with below average IQ ▪ No TD control group

Theme	Authors *(Year; Location)*	Sample Sizes (*N*) ASD Group *(n boys: n girls)*	Sample Sizes (*N*) Control Group *(n boys: n girls)*	Age Range *(Years)*	Measures	Main Outcomes	Limitations/ Bias
						and completed less categories on WCST than boys	
	Messinger et al. (2015; USA)	252 (203:49)	1572 (1317:255)	0–1.5	▪ ADOS ▪ MSEL	▪ 3:1 male to female odds ratio in ASD recurrence due to familial factors ▪ Girls in both high risk and low risk sibling groups had higher cognitive functioning abilities than boys in both groups ▪ In both groups girls had fewer RRBIs than the boys	▪ Smaller sample and fewer females in ASD and control group ▪ Missing data on both measures ▪ Findings may not be generalisable to older cohorts
	Ross et al. (2015; USA)	73 (58:15)	102 (55:47)	5–17	▪ WASI ▪ ADI-R ▪ ADOS-G ▪ Stimuli & Task Eye-tracking	▪ In both groups, girls were significantly better at recognising words under audio-visual listening conditions than the boys ▪ Task performances by girls with ASD were reportedly less effected under audio-visual conditions	▪ Small samples, with fewer females in ASD group ▪ Findings may not be generalizable to individuals with below average IQ ▪ Findings may not be generalisable to other cultures

Theme	Authors *(Year; Location)*	Sample Sizes (*N*) ASD Group *(n boys: n girls)*	Sample Sizes (*N*) Control Group *(n boys: n girls)*	Age Range *(Years)*	Measures	Main Outcomes	Limitations/ Bias
Core ASD Symptomatology	Harrop et al. (2015; USA)	80 (40:40)	N/A	1.8–4.9	▪ ADOS-II ▪ MSEL ▪ ESCS ▪ SPA	▪ No significant differences found between girls and boys on measures of joint attention, requesting behaviours, social communication skills and play	▪ Small sample size ▪ Findings may not be generalisable to older cohorts and individuals with average or above IQ ▪ Did not control for possible differences in data distribution ▪ No TD control group
	Hiller et al. (2015; Australia)	152 (92:60)	N/A	6–17	Online Survey	▪ Significant differences between pre-diagnosis concerns of parents of boys and girls ▪ Significant differences in social strategies reportedly used by boys and girls to manage in pre-school ▪ Significant differences between boys and girls with ASD in restrictive interest types	▪ Small sample, with fewer females ▪ Retrospective and subjective parent reported data increased potential for recall bias ▪ No direct observations across a variety of social contexts ▪ No standardised measures used ▪ Findings may not be generalisable to individuals with below average IQ with lower adaptive functioning abilities ▪ No TD control group

Theme	Authors *(Year; Location)*	Sample Sizes (*N*)		Age Range *(Years)*	Measures	Main Outcomes	Limitations/ Bias
		ASD Group ***(n boys: n girls)***	**Control Group** ***(n boys: n girls)***				
	Postorino et al. (2015; Italy)	60 (30:30)	N/A	2–5.4	▪ ADOS-G ▪ GMDS-ER ▪ PSI-SF ▪ CBCL ▪ VABS-SF	▪ No significant interactions between gender and time for predicting parental stress, severity of ASD symptoms, development, child behaviour problems or adaptive skills ▪ Girls showed considerable development in their cognitive abilities from time 0 to 1 – more so than the boys	▪ Small sample size ▪ Clinically referred sample from a single source ▪ Findings may not be generalisable to older cohorts ▪ Mixed sample for intellectual ability ▪ Retrospective and subjective parent reported data increased potential for recall bias ▪ No TD control group
	Reinhardt et al. (2015; USA)	288 (234:54)	223 (164:59)	0–3	▪ CSBS ▪ ADOS ▪ MSEL ▪ VABS	▪ No significant gender differences found in ASD group across measures of early social communication, developmental functioning, adaptive functioning, and ASD symptoms	▪ Fewer females in samples ▪ ADOS more of a diagnostic tool than measure of symptom severity ▪ Only 30% of control group completed ASD diagnostic assessment ▪ Retrospective and subjective parent reported data increased potential for recall bias

Theme	Authors *(Year; Location)*	Sample Sizes (*N*) ASD Group *(n boys: n girls)*	Sample Sizes (*N*) Control Group *(n boys: n girls)*	Age Range *(Years)*	Measures	Main Outcomes	Limitations/ Bias
ASD Risk Factors	Zachor et al. (2013; Israel)	615 (532:83)	N/A	1.5–18	▪ ADOS ▪ ADI-R ▪ MSEL ▪ VABS ▪ BS ▪ WISC-III/ IV WPPSI ▪ SB ▪ KABC-II	▪ No significant associations between gender and selected ASD risk factors: Parental ages; ASD family history; Birth order; Low birth weight & prematurity; Gestational age	▪ Fewer females in sample ▪ Potential bias in selection of risk factors included – alternative risk factors may be equally/ more important ▪ Wide age range with no longitudinal measure of change over time ▪ Retrospective and subjective parent reported data increased potential for recall bias ▪ No TD control group
Age at Diagnosis	Mishaal et al. (2014; Israel)	551 (480:71)	N/A	1.25–6	▪ ADOS ▪ ADI-R ▪ VABS	▪ No significant gender differences in age at diagnosis	▪ Fewer females in sample ▪ Findings may not be generalisable to older cohorts ▪ Lack of cognitive and adaptive skill measurement ▪ Potential bias in selection of 7 predictors included, which may only account for small

Theme	Authors *(Year; Location)*	Sample Sizes (*N*) ASD Group *(n boys: n girls)*	Sample Sizes (*N*) Control Group *(n boys: n girls)*	Age Range *(Years)*	Measures	Main Outcomes	Limitations/ Bias
							proportion of the variance ▪ Retrospective and subjective parent reported data increased potential for recall bias ▪ No TD control group
Access to Services & Parental Distress	Zamora et al. (2014; USA)	166 (89:77)	N/A	1–15	▪ PSI-3-SF ▪ ADOS-G ▪ Medical History Form	▪ No significant gender differences in number of services received ▪ Parental distress and parent-child dysfunctional interaction rated significantly higher by parents of girls ▪ Fewer services received predicted higher levels of parental distress for parents of girls, but not for parents of boys	▪ Small sample with fewer females ▪ Did not assess for co-morbid conditions of child and parent ▪ No direct observations across a variety of social contexts ▪ No measure of intellectual ability ▪ Retrospective and subjective parent reported data increased potential for recall bias ▪ All parents included in the study were mothers ▪ No TD control group

ADI-R: Autism Diagnostic Interview-Revised; ADOS: Autism Diagnostic Observation Schedule; ADOS-G: Autism Diagnostic Observation Scale-Generic; ADOS-II: Autism Diagnostic Observation Schedule – 2nd Edition; ADOS-T: Autism Diagnostic Observation Schedule-Toddler Module; ASD: Autistic Spectrum Disorder; ATEC: Autism Treatment Evaluation Checklist; BS: Bayley Scales of Infant Development; CARS-TV: Childhood Autism Rating Scale – Tokyo Version; CBCL: Child Behaviour Checklist; CSBS: Communication & Symbolic Behaviour Scales Developmental Profile; CSHQ: Children's Sleep Habits Questionnaire; DBC-P: Developmental Behaviour Checklist, Parent Version – 2nd Edition; ESCS: Early Social Communication Scales; GMDS-ER: Griffiths Mental Development Scale-Extended Revised; IQ: Intelligence Quotient; KABC-II: Kaufman Assessment Battery for Children – 2nd Edition; MRI: Magnetic Resonance Imaging; MSEL: Mullen Scales of Early Learning; N/A: Not Applicable; PSI-3-SF: Parenting Stress Index-3 – Short Form; PSI-SF: Parent Stress Index – Short Form; RRBIs: Restricted Repetitive Interests and Behaviours; SB: Stanford-Binet Intelligence Scales; SCAS-P: Spence Children's Anxiety Scale, Parent Version; SIB-R: Scales of Independent Behaviour-Revised Short Form; SPA: Structured Play Assessment; TD: Typically Developing; VABS: Vineland Adaptive Behaviour Scale; VABS-II: Vineland Adaptive Behaviour Scale – 2nd Edition; VABS-SF: Vineland Adaptive Behaviour Scale-Survey Form; WASI: Wechsler Abbreviated Scales of Intelligence; WCST: Wisconsin Card Sorting Test; WISC-II, III & IV: Wechsler Intelligence Scale for Children – 2rd, 3rd & 4th Editions; WPPSI: Wechsler Preschool and Primary Scale of Intelligence; WPPSI-III: Wechsler Preschool and Primary Scale of Intelligence – 3rd Edition.

Supplemental File C

Table 3. Review adherence to PRISMA checklist as relevant to a systematic and qualitative approach (in the style of Moher et al., 2009).

Section	Topic	Checklist Item	Page Number(s)
Title	Title	Identifies review as systematic	2
Abstract	Structured Summary	Provides a structured summary	32
Introduction	Rationale	Describes rationale for review in context of what is known to date	33–36
	Objectives	Describes what is being addressed by review	36
Method	Eligibility criteria	Provides inclusion/exclusion criteria and rationale	36
	Information sources	States information sources (i.e. databases, dates, etc.)	36–37
	Search	Provides search strategy terms for replication	37
	Study selection	Demonstrates selection process	37 70
Results	Synthesis of results	States method of combining and synthesising data of studies (i.e. 'qualitative synthesis')	37

Section	Topic	Checklist Item	Page Number(s)
Results	Study selection	States numbers of studies screened and selection processes (i.e. Figure 1)	37 70
	Study characteristics	Provide study characteristics (i.e. sample sizes)	37–38 72–81
	Risk of bias within studies	Assess risk of bias/ limitations of each study	38–49 72–81
	Results of individual studies	Provides summary of outcomes for each study	38–49 72–81
Discussion	Summary of evidence	Synthesises and summarises outcome of review and the relevance of these findings for the reader	49–50
	Limitations	Explores limitations at study-, outcome-, and review-level	50–52 72–81
	Conclusions	Provides an overall summary of the results in the light of previous reviews (i.e. research and clinical implications)	50–53

Section Three:

Empirical Paper

The use of social strategies by women with high-functioning autism

Aimee J Hooper[1] [2] and Kristina Cole[2]

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Funding: No funding was provided for this research.

Conflict of Interest: The authors declare that they have no conflict of interest.

Acknowledgements: The researcher AH would like to thank the participants who kindly took part in the study, the professionals who assisted with the recruitment stage of the project, co-author KC for her assistance and support throughout the project, and the staff team at North Wales Clinical Psychology Programme, Bangor University.

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Author Submission Guidelines

Journal of Autism and Developmental Disorders

Editor-in-Chief: Fred R. Volkmar

ISSN: 0162-3257 (print version)
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Journal no. 10803

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1. Order of manuscript pages

Title Page with all Author Contact Information & Abstract with keywords and the corresponding author e-mail information.

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Appendix

Figure Caption Sheet

Figures

Tables

Author Note

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- Article by DOI

  Slifka, M. K., & Whitton, J. L. (2000) Clinical implications of dysregulated cytokine production. Journal of Molecular Medicine, doi:10.1007/s001090000086

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- Online document

Abou-Allaban, Y., Dell, M. L., Greenberg, W., Lomax, J., Peteet, J., Torres, M., & Cowell, V. (2006). Religious/spiritual commitments and psychiatric practice. Resource document. American Psychiatric Association. http://www.psych.org/edu/other_res/lib_archives/archives/200604.pdf. Accessed 25 June 2007.

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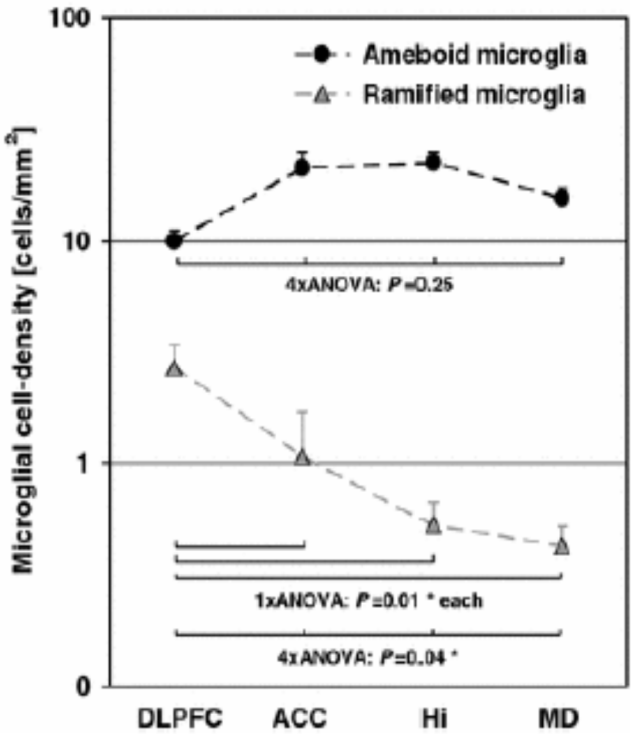

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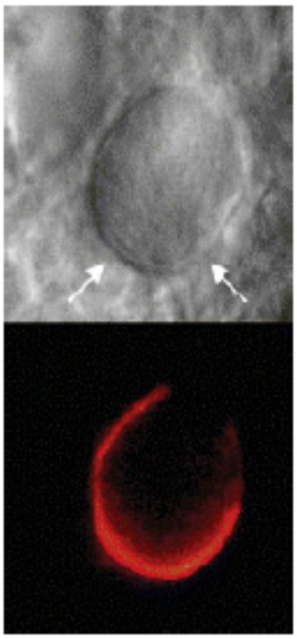

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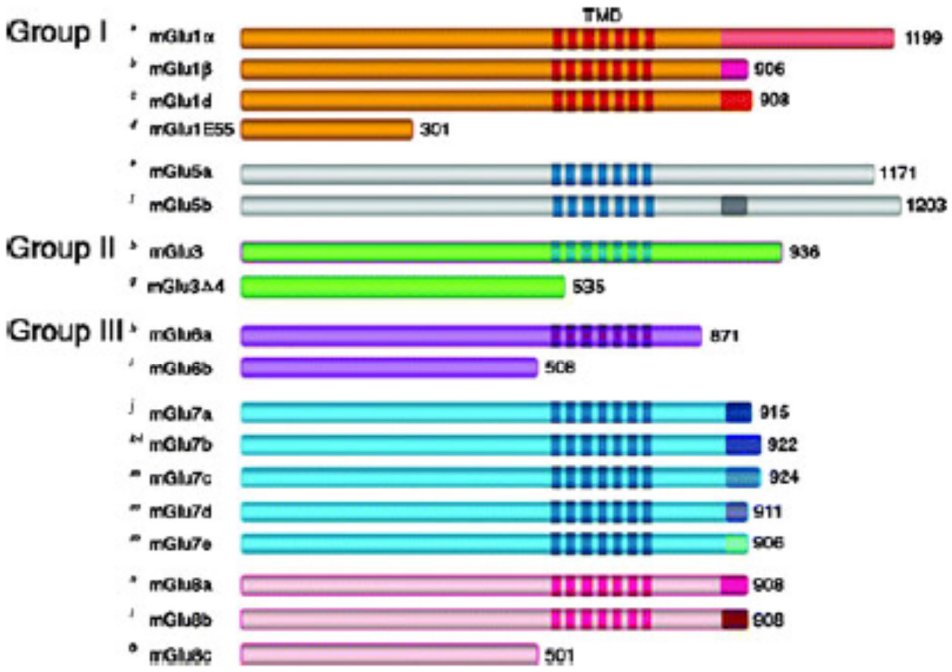

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Abstract

This study explored whether women with high-functioning autism (HFA) use certain strategies to cope in social situations and if so the nature of such efforts. Semi-structured interviews were conducted in North Wales with eleven women aged 19 to 60 years old with HFA. Using an explorative thematic analysis method, the following themes were proposed: (*a*) The struggle to understand the intricacies of social etiquette; *(b*) Trying to fit in – Keeping your challenges quiet; *(c*) I am who I am – Being open and honest; *(d*) Relying on others in social situations; and *(e)* Strategies or no strategies – It all has an effect. The clinical and research implications of these findings are discussed.

Keywords: High-functioning autism; females; social skills; strategies; camouflage

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The Use of Social Strategies by Women with High-Functioning Autism

Autism is a neurodevelopmental disorder characterised by deficits in social communication and interaction, and restrictive and repetitive patterns of behaviour, interests or activities (American Psychiatric Association; APA 2013). In line with the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; *DSM–5*; APA 2013), individuals who receive an Autism Spectrum Disorder (ASD) diagnosis can present with differing levels of symptom severity. This ranges from those who require support in everyday living, to those with milder difficulties who may function with minimal support.

Individuals with a clinical diagnosis of ASD of milder severity or Asperger syndrome (AS) are often referred to in the literature as having high-functioning autism (HFA). Individuals with HFA will generally present without severe language impairments or intellectual disabilities (Frith 1991), but usually experience difficulties knowing how to interact with and understand others in social situations.

There are debates in the literature over whether there are significant differences between AS and HFA (Ghaziuddin and Mountain-Kimchi 2004; Howlin 2003; Koyama et al. 2007; Ozonoff et al. 1991). AS is a clinical diagnosis in the *International Classification of Diseases* (*ICD–10*; World Health Organisation 2015), but not in the *DSM–5* which has now moved to using ASD (of milder severity). Therefore, for the purposes of this study and due to the ongoing uncertainty surrounding this debate, the term HFA will be used to refer to all high-functioning autistic individuals with a diagnosis of ASD (of milder severity) or AS.

Gender

The literature proposes a male to female ratio of 4.3:1 respectively in HFA (Fombonne 2003). This gender imbalance has been seen from the very beginning of the

research literature (Kanner 1943). Recent research highlights possible gender differences in HFA in the type of restrictive and repetitive behaviours, interests and activities (RRBIs) exhibited, and differences in executive functioning, empathising and socio-communicative abilities (Cridland et al. 2014; Lai et al. 2011; Van Wijngaarden-Cremers et al. 2014). Of 113 reviewed studies, Kirkovski and colleagues (2013) found that 78.8% provided support for a differing profile for females with HFA due to presenting with fewer RRBIs and externalising behaviours than males, with more stereotypical female interests.

The literature suggests that current ASD diagnostic criteria and assessment tools may be 'male biased' and geared towards a heavily male orientated understanding of ASD (e.g. Goldman 2013; Kirkovski et al. 2013; Rivet and Matson 2011; Werling and Geschwind 2013). There are also clinical observations and personal accounts of women receiving an autism diagnosis later on in life, or being misdiagnosed with other conditions (Attwood et al. 2006; Wilkinson 2008). If women with HFA are being missed, misdiagnosed or diagnosed later on in life, this could be due to the aforementioned male bias in the clinical understanding and assessment of HFA, or alternatively, there could be other explanations.

Superficial Sociability

One possible explanation in the literature is that females with HFA present differently to males with HFA in social situations due to attempts at presenting as superficially skilled in social interactions. This is often referred to in the ASD gender literature as 'camouflaging' (Kopp and Gillberg 1992; Lai et al. 2015). For example, there is evidence to suggest that girls with ASD are more adept at conducting pretend play and social imitation than boys with HFA (Cridland et al. 2014; Solomon et al. 2012), and Mandy et al. (2012) found that young girls with HFA were making efforts to compensate for certain social limitations in a school environment. There is also evidence of adolescent and adult females with HFA observing and

mimicking the behaviour of others, trying to present as socially skilled, or trying to go unnoticed in social situations (e.g. Attwood et al. 2006; Hiller et al. 2015; Müller et al. 2008). Interestingly, Lai et al. (2011) found that women with HFA presented with fewer socio-communication difficulties and self-reported more autistic traits than men with HFA. In addition, some researchers suggest that females may experience more social pressure than males with HFA to be empathetic and develop friendships which rely heavily on reciprocity and communication (Kopp and Gillberg 1992).

Other examples of females with HFA camouflaging have been shared in alternative media including autobiographies, radio interviews and online forums. For example, Grandin (1992) reports achieving social success through rote learning of how to act in different situations, and the use of phrases and small talk recalled from previous conversations. Willey (1999) also describes how she camouflaged her social confusion in adolescence by acting out different personas and hiding on the periphery of groups to go unnoticed.

Gaps in the Literature

To date there is minimal research specifically asking women with HFA whether they try to present as superficially skilled in social situations and if so the nature and reasons for this. Research exploring this might further our understanding of women with HFA and whether they do present differently to men with HFA, potentially providing an explanation for their not receiving a timely diagnosis.

Research Question

The research question for this study was the following: What strategies or techniques do women with HFA use in order to cope in social situations, and when, how and why do they do this?

Method

Approach

This qualitative study employed a Thematic Analysis (TA) method within an experiential paradigm. The researcher approached the TA by staying close to the lived experiences reported in participant narratives, whilst simultaneously acknowledging that such real-life perspectives (including the researcher's own) were subjective and could be influenced by other factors (Braun and Clarke 2006, 2012, 2014; Clarke and Braun 2013). The research question, sampling and data collection methods and sample size, were all in line with the TA method.

Participants

Eleven consenting high-functioning autistic adult women from North Wales participated in the study (please see Table 1; Appendix A). All participants had received a formal diagnosis of ASD or AS in adulthood prior to participation. Diagnoses were confirmed through the screening of original autism assessment reports. The number of years passed since participants had received their diagnosis ranged from a few months to three years. Any indicators of low intellectual functioning or learning difficulty indicative of more severe impairment, had already been ruled out during the comprehensive clinical assessment process conducted by experienced clinicians.

Participants from all ethnic and cultural backgrounds were able to take part in the study. Participants spoke English and were aged between 19–60 years old; three were in their twenties, three in their thirties, three in their forties, and two in their fifties. Ten participants were of British nationality and of white ethnicity, and one participant was of British-Cypriot dual nationality and of white (other) ethnicity. Five participants were married and five had one or more children. Two participants were students, one was retired, and seven were self-

employed, volunteering or working for others, either full or part time. One participant did not wish to comment on her occupation or marital status.

Procedure

This study received ethical approval from Bangor University School of Psychology ethics committee and the NHS Wales Research Ethics and Research and Development committees, before commencing (see Section 5 Ethics Appendices).

Participants were approached and recruited via four senior NHS Clinical Psychology professionals. A local ASD support worker also supported the recruitment process. Potential participants were contacted by the professionals by telephone or letter (Section 5; Appendix N), to ask whether they would like to know more about the study and possibly take part. The letter method was the most commonly used approach taken by the professionals. Interested participants were then sent out a study information pack by the researcher, which included an introductory letter and a participant information sheet with a return slip for those wishing to take part (Section 5; Appendices O & P).

A consent form was discussed with and given to participants at the beginning of each interview prior to audio recording to confirm they were aware of their rights, the study protocol, confidentiality and the limits of this, and to re-ascertain that they were participating voluntarily and not through coercion (Section 5; Appendix Q). Semi-structured interviews conducted in English were used in order to collect the participants' experiences. The interviews took place at either Bangor University or an NHS mental health resource centre in Llandudno and lasted approximately 45 to 60 minutes. Participants were asked set demographic and semi-structured interview questions from the interview schedule, with additional prompts for elaboration where appropriate (Section 5; Appendix R). This

flexibility ensured that the researcher did not strictly dictate what the participants talked about, whilst still providing some structure with regards to addressing the research question.

Data Analysis

Each research interview was transcribed verbatim and checked for accuracy. In line with the researcher's critical realist and contextualist approach and the recommendations of Clarke and Braun (2013), the TA was conducted in the following manner:

- Familiarisation of the interview transcripts by reading, re-reading and making familiarisation notes (Section 6; Appendix A).
- Systematic *semantic* and *descriptive* coding of the transcript data in relation to the research question (Section 6; Appendix B).
- The elimination and retention of codes in line with the research question.
- Collating of codes with accompanying quotations.
- Searching for initial themes from codes and mapping them out.
- Reviewing and refining initial themes into overarching themes, themes and sub-themes.
- Defining and naming themes (Table 2; Appendix B).

Due to the subjective nature of qualitative research, the researcher kept a reflexive diary throughout the course of the study, and investigator triangulation (Golafshani 2003; Guion 2002; Jonsen and Jehn 2009) was conducted prior to theme development, whereby two transcripts were independently coded by the research supervisor. Assigned codes were then compared and discussed jointly with regards to overarching similarities and differences in coding styles. This was conducted to sort and validate the assigned codes and to further enhance the credibility of later theme reviewing, refining and selection processes. The researcher also acknowledged that despite conducting investigator triangulation, the thematic

process was inherently open to subjectivity and such bias cannot be offset in its entirety within an experiential paradigm (Clarke et al. 2015).

Findings

The reasons *why* participants reportedly used various strategies to cope in social situations included a commonly shared experience of struggling to understand social behaviour and uncertainties regarding how to be around and interact with others in social environments.

Varying types of coping strategies were reportedly used in social interactions, and regardless of which form of coping was used the responses revealed a range of scenarios *when* they were more likely to use such strategies: (*a)* with individuals whom they shared fewer similar interests; (*b)* more so in social groups more than in one to one interactions; *(c)* frequently at work or outside of the home environment; and *(d)* more so in face to face interactions than through online or other written forms of interaction.

Insert Fig.1 here

As can be seen in the final thematic map (Fig. 1; Appendix C) and thematic table (Table 3; Appendix D), five themes are proposed which will now be described and interpreted in more detail.

Overarching Theme: The Struggle to Understand the Intricacies of Social Etiquette

Feeling clueless. Seven participants reported feeling clueless in social situations, reportedly finding it "…difficult to understand… the intricacies of social etiquette" (P2), "…understanding what people do and what people say and how they are and how you

interpret their body language" (P7). One participant recalled feeling lost in social situations at school: "some people say things like 'oh he fancies her, you can tell how he's looking at her' and I'd say 'how can you tell?'…not having a clue what was going on most of the time" (P10).

Lacking awareness sometimes led participants to feel confused or frustrated: "apparently it's polite to ask but they don't actually want to get you stuff and I'm like well (sigh) why are you asking then? …this is what other people mean and then apparently it doesn't mean that…it gets confusing" (P3).

Making mistakes. Linked to this reported feeling of social cluelessness, many participants also reported making mistakes in interpreting others' behaviour or communications, or doing something which was viewed by others as socially inappropriate. Of the errors reported, some were from childhood: "…when people at school gossiped about each other to me…I just told everybody what everyone said and then I ended up being the bad person" (P4). Some mishaps were more recent:

> …like if I ask someone a favour and they say yes that's it then as soon as they say yes I'm like right, I don't think to say 'thanks, cheers, you're a life saver' or something. As soon as they agree it's like right conversation over. – P5

Theme Two: Trying to Fit in – Keeping your Challenges Quiet

Hiding the real me – it's all an act. Nine participants reported hiding their problems with understanding social etiquette due to a desire to fit in and attempts to meet perceived social expectations, due to a fear of being judged or misunderstood by others: "there are women who are still worried that their diagnosis will bring in social services…you keep your challenges very very quiet" (P8).

Some participants reported doing this by trying to blend in and go unnoticed by others and reduced any self-directed social attention by tempering natural behaviours. Alternatively, others did this by putting on a social act, sometimes mimicking others or fictional characters, or by being a social butterfly oscillating from one social group to another. Analysis of the data highlighted that these strategies were often perceived as being effective. The women had used them from a young age into adulthood at work or group-based social events and particularly with strangers.

Of those who tried to blend in and go unnoticed by others many reported being good at this "behind the scenes stuff" (P10), whereby they would be "…very quiet…just sit there nice and quietly…blended in as much as possible…I did a very good job at blending in…the teachers didn't notice me" (P11).

Many participants reported tempering their natural behaviours by not being as truthful around others as they would naturally want to be, would force themselves to be sociable, and would not listen to instinctual behavioural impulses. One participant insightfully described the experience as thus: "Over the years I've learned to temper my responses…others can find them hard to cope with…so it's easier to supress them" (P2).

For those who hid their social skills limitations by putting on a social act, some described this as a conscious effort, which served to build confidence. One participant reported "fitting into the mould" to "be what they wanted me to be" with previous partners and current family members: "…for each one of them people I was a different person…no matter what I did I was having to put an act on all the time…I don't have to put a mask on to be with my children" (P8).

Putting on an act also appeared to have its side effects:

> …it's all an act but I don't know how to drop the act. I've done it for so long I don't know how to drop it...I put an act on and I can't remember what act I put on last time I saw them…you have to try and remember everything from the last time you saw them. Who was I? Who was I? – P5

Interestingly, seven participants reported mimicking others, or acting out the personas of fictional characters, in order to promote their social act. They reported doing this unintentionally, reporting that it was effective and "…more efficient cos you don't have to use all your extra brain energy" (P3). They reported doing this by re-using other people's small talk or topics from previous conversations, and mimicking mannerisms. Three participants also found becoming a fictional character helpful in social situations:

> …if I want to be more confident it can help to pretend to be a fictional character…I slouch a bit when I'm being normal me…she's a pretty confident person [female character from Dr Who]…it can be easier to pretend to be like her if I want to be a confident person talking to people. – P3

Physical strategies. Another strategy that eight participants reportedly used involved physically doing certain things, before or during social exchanges. For example, four participants used online resources to aid them in learning social skills: "to actually get out into the community (laugh) I used YouTube…there's lots of bite sized courses on there about how to influence people…how to use positive body language…how to communicate and how not to communicate…very much scripting" (P8).

Some also used online resources to get social guidance from others: "'Mumsnet'…it's like social etiquette online…there's one on there called 'Am I being unreasonable?'…I get a lot of it from that…I'll read stuff and think oh I thought that was perfectly fine or something, but no turns out it's not" (P5).

Some participants reportedly tried to manage their anxiety in social situations by pacing themselves or distracting and keeping themselves busy: "I was a library helper…something to do at lunch time and break time rather than go and talk to people…something to do that's like not talking to people and not just sitting there staring, doing nothing" (P3). Some participants used these strategies at work:

> I took a laptop into my meetings…it gave my brain something to think about rather than think 'I'm in a meeting, I'm in a meeting'…doing that was a coping strategy…something to stare at, didn't have to look at the people, just hear what they were saying and write it down. – P10

Particular eye contact strategies or the wearing of certain items of clothing to reduce sensory sensitivity were also reported: "I would try and sort of look at something near the person…for a few seconds hold my gaze a bit longer…it does help" (P2). One participant explained how in social environments "…earplugs is a must…dark glasses is a must…heavy weights…ankle weights…a heavy leather jacket that's got pebbles in the pocket…weight really makes an impact on calming your system" (P8).

Alternatively, some participants made efforts to avoid socialising altogether:

> I've always gone out of my way to avoid social situations…avoidance whenever possible…I used to organise conferences but I never went to them…team meetings I avoided at all costs…it was the milling around, the networking…I would go out the door and go to the loo and sit there for twenty minutes or something. – P10

Cognitive strategies. Participants' hypervigilant thoughts when entering a conversation appeared to be fast and constant: "…oh ok should I be nodding, should I be replying to this…what should I be doing with my hands…should I try and get involved in the conversation or is that rude, should I just wait to be invited?" (P3). One participant explained

how: “I couldn’t focus my brain. I found I was too busy thinking about the last conversation…You’re constantly thinking about what’s just happened not what is happening” (P5).

To deal with the over thinking, participants reported using particular cognitive strategies, to better pre-empt social interactions, or to know how to respond or comprehend in the moment. Cognitive strategies, such as checking meanings and looking for cues or signs from others, were reportedly used before, during and after socialising:

> I’m looking at body language…I had to pick up on the signs…a bit like motivational interviewing…but a body language version…I have to kind of remind myself of things to fit in socially…give the person a chance to talk, so like a little mental check that I need to kind of stop and listen. – P11

Another approach involved cognitive preparation in advance about where they were going, who they might meet, what they might be asked, what they might say, how they might stand or hold themselves, and what things they might do to keep busy. Looking for signs of a shared common interest was reported by all as being key to engaging effectively with others, as it helped them focus on a particular topic they enjoyed or knew a lot of information about: “if you know you are going to be interacting with someone with a common interest as you that is far easier” (P2); so “if I don’t know someone and they start talking about say the artist Turner…then it will be ‘oh I can talk to you now’ (laugh, sigh)…but if there’s nothing then it’s really difficult” (P6).

Theme Three: I Am Who I Am – Being Open and Honest

Being true to myself. Although participants reported putting on a social act and using other strategies to get by, nine participants also reported finding honesty, openness and “acting the way I always have” (P3) equally helpful at times: “I am who I am…I don’t blend in

now…I'm happy and I don't need to be anything else" (P11). One participant expressed that: "…things like something looking alike or trying to be the same, well I don't care…I wear what I like, when I like, if I like…" (P1), and another explained how: "…I just tell them to bugger off it's my life…I don't really care what people think of me…I am who I am…you're still the same you…you're still the same person…" (P4).

Interestingly, three participants reported never having camouflaged in order to hide their social difficulties or present as socially skilled, as mimicking or pretending to be someone or something else felt dishonest: "mimicking is…to me a way of being false…it's not something that I think I've done or ever been inclined to do" (P2).

Dropping the act. Two participants openly described how they had dropped previous social acts or attempts to blend in: "I wouldn't say I blend in or am trying to blend in purposefully anymore, that ended when I left school…at least more than ten years…of being myself…it's not as much of a problem anymore" (P11). They insightfully explained why this was no longer a conscious strategy for them: "I just ended up thinking well I'm not happy being that person that's blended in all the time…I don't wanna do it and I just thought I'm really unhappy like that" (P11).

Regrettably, dropping the social act and being herself had negative consequences for one participant:

> …no matter what I did I was having to put an act on all the time…so I just stopped…and I lost an awful lot of friends…instead of shutting up like I'd always done I actually told them my views…people don't like it when you suddenly turn from being this quiet…mouldable person that they can do whatever they want with to being your own person. – P8

Saying it as it is. Some participants reportedly preferred being honest in conversations with others where they felt comfortable to, and some felt that it fostered their connections with others in their personal lives: "…be open and honest about who and what you are…so people will…cater for you more easily…to be open and honest can really have its benefits" (P2). Others used honesty and openness in their communications in the workplace: "…if I think that you're not doing something right…I will just tell it as it is…" (P7), and how:

> …another thing that I think helps is I never say I'll do something if I can't do it and I think that's really important with building relationships and trust with anyone erm, because I'll say oh well I'll try and do this if I think I can or I'll say I'll do it if I know I can. And if I can't, then I'll always ring them up and explain why I can't do it. – P11

Although honesty and openness in conversation was a preferred or natural option for some, it also had its drawbacks and frustrations: "I don't censor what I talk about…I don't protect people from squeamishness…I've got no nine pm watershed. That's what it is…I can offend people (laugh)" (P5). One participant recalled how:

> my mum used to say…I was like a bull in a china shop…jump in with both feet and that that that's just me…I've always been like that I just say what I think…it affects people's feelings…after when people have told me…I feel bad that I didn't mean to do that but I do it anyway. – P9

Theme Four: Relying on Others in Social Situations

The socio-emotional guide. Eight participants reported that from childhood through to adulthood they relied on friends, family members or partners who would often take on the role of an emotional and social guide.

For the women this commonly involved being told what to say or do in a particular social situation or being advised when they had said or done something socially unacceptable or made other social errors: "…there are phrases that erm I'm told, 'so 'however' is a word that I've been introduced to…instead of saying 'but I think you're wrong' I'm supposed to say 'however, if you were to do it this way'…" (P7).

For some of the women, parents continued to play a vital role throughout adolescence and adulthood for giving social advice: "…my dad usually says to me just say hello and walk on and that's what he said and I do that I just go hi and I walk on…". One of the participants interestingly explained how:

> When I was younger my mum gave me lots of advice about what to say to people…cos I always tell people too much…mum would tell me in friendships what I need to be saying and what I shouldn't…nowadays…she just tells me to be quieter cos she knows I'm loud and people find that tiresome. – P11

The women also reported sharing particular signals or cues with shared meanings with their guide, which they used during a social event: "I'll start looking at my husband or my sister who's with me for guidance on have I talked about that too much?...that's kind of what helps me…to bring me back…Or he will raise his eyebrows at me… it can just be a hand gesture, sometimes it can just be a motion…as though to say I think you've said enough" (P9).

The guide would often explain or advise what others had meant in their interactions if they had misunderstood and would help them out with understanding their own or others emotions following social exchanges: "she was sort of my emotional guide if you like…somebody dies in our class…she was like keep it calm, everybody's upset today cos this person died…sort of helped me tone it down a bit" (P10).

The rescuer. Occasionally, the person acting as the socio-emotional guide would also take on a rescuing role, whereby they would step in and talk on the participant's behalf, take them away from a difficult social situation in order to protect or distract them, or would help to reduce their social anxiety: "…in the early stages I found she was stepping in quite a lot to speak for me to explain for me…because they know me they're able to speak for me when I can't speak…I need that help" (P7). One participant recalled how "…when I was a teen…some people would call for me occasionally and I told my mum to go tell them I can't go…so I'd get my mum to sort of fire the bullets, yes. She would tell them to go away".

The rescuer was often a partner, parent or friend:

> I remember when we bought the wedding and he [husband] was like are you gunna be alright, but are you really gunna be alright with all those people...I just let me mum organise it, I said to her you deal with it, so she organised it. – P5

Curiously, one participant described how her supervisor would sometimes take on the role of social rescuer in the workplace: "my supervisor always worried that I wouldn't interpret the situation very well …so thankfully I was rarely put in that situation" (P11).

Theme 5: Strategies or No Strategies – It All Has an Effect

Positive outcomes. Irrespective of the type of strategies used, participants reported that they improved with time and experience: "…it's like you've got to learn. It's not instinctive. I've been around a long time so I've figured things like that…you see that then you learn to do this…I tend to take literally what I've learnt over the years" (P10). One participant positively reported how her strategies had become to feel more like natural behaviour following years of practice: "I can actually use sarcasm and I don't always take things literally…you know how to use it…learnt behaviour" (P5).

Negative outcomes. Nine participants described how despite their use of particular strategies, their disadvantages outweighed the benefits as they were not always effective and the effortful nature of using and learning them often exacerbated unwanted emotional and physical symptoms: "It's tiring, it's wearing, and you can see why so many…neuro-diverse women end up with chronic health conditions" (P8). Social exhaustion was experienced by many, which appeared to be linked to the use of cognitive strategies: "once your brain's done, your brain's done...I used to just stare at the wall when I got home" (P6). Connected to this experience of social exhaustion was "masses of anxiety" before going into a social situation and difficulties "…getting the motivation to go into the social event" (P8).

Over half of the participants also reported being misunderstood by others despite using particular strategies in social situations: "People misjudge my eye contact for what it's not…I get told I'm rude for leaving my sunglasses on…I will say…I will explain to you why I need to wear dark glasses" (P8). In connection with being misunderstood, participants described how their strategies would not always work: "…talking about the same things…trying to laugh at things other people were laughing at…That's the problem (laugh). I tried very hard but I don't think I was very good at it" (P11). One participant emotively explained how:

> …they [strategies] make it easier for you to fit into the world, but they don't make it easier to fit into the systems like education…putting all these things in place are great but you still need people to work with you and if people aren't working with you no amount, no matter how many adjustments you put in, if people aren't working with you it's not going to work. – P8

Discussion

Summary of Findings

The aim of this study was to explore whether women with HFA use particular strategies in order to get by in a social world and if so the nature of these. Five interrelated themes were identified in answer to the initial research question, of which the overarching theme appeared to be the universal difficulties experienced by the women in understanding social etiquette. Linked to this all-encompassing sense of social confusion were tendencies to use particular strategies involving: *(a*) putting on a social 'act' and doing certain things to try and blend in and hide their difficulties; *(b*) relying on significant others to guide or rescue them in difficult social situations; and *(c*) stopping or not making efforts to hide or fit in and instead being true to themselves through honesty, openness and dropping previously used social acts.

These strategies had either been learned from other people, online resources, or through personal experiences of learning and knowing what is effective. Many of the women were using the majority of these methods intentionally and particularly so in group situations, which were often dependent upon the social context and their mood at the time. As all of the women interviewed had been diagnosed in adulthood, most of them had used their particular coping strategies from a young age, despite not knowing why they felt different to their peers or why it was hard to be around others and interact on a social level.

It would appear that HFA females have a keen sense of, or have been told, that they have social limitations. They report engaging in vigilant checking, internet searching, mimicking and looking for common interests before and during interactions. Many continue to rely on significant others to help them negotiate social environments and on some occasions social encounters are avoided all together. The emotional and physical toll

resulting from such efforts should not be underestimated and can perhaps be encapsulated in the comment: "…I used to just stare at the wall when I got home…my boyfriend…he doesn't think it's healthy…it probably isn't I guess…" (P6).

Many of the women moved between trying to camouflage and trying to be true to themselves. This interesting relationship of opposites highlighted that some of the women were in a see-saw between on the one hand wanting to be open and honest, but on the other highly anxious about being judged or misunderstood. As a result they would hide their difficulties to appear neuro-typical.

Sadly, despite whether the women used particular strategies to camouflage or not, they all experienced more negative outcomes from their efforts and interactions with others than positive ones. These often involved being misunderstood, feeling overwhelmed, exhausted or finding their strategies ineffective for social success.

Limitations

It is important to outline any limitations of this study. The participants were a self-selecting sample of mainly white British women which implies that the findings may not be as applicable to women with HFA from other cultural and ethnic backgrounds. There is also the possibility that many of the women who chose to take part did so because they used social strategies of which they were aware, and as such felt comfortable talking about this. It is not known why some selected not to participate but it is possible that some women were not interested in discussing their experiences because they were coping well, or they may have found the prospect of being interviewed too daunting.

A related issue concerns the potential risk from the outcomes presented to over pathologise the social difficulties experienced by women with HFA, by potentially focusing

less on their successes and strengths. At least one participant implied that she had benefited by practicing skills which she felt had become more natural with time.

Contributions to the Literature

This study was conducted in light of tentative evidence from relevant literature and clinical observations suggesting that there may be a different behavioural phenotype (i.e. tendencies) for females with HFA, compared to males with HFA (Cridland et al. 2014; Kirkovski et al. 2013; Lai et al. 2011; Van Wijngaarden Cremers et al. 2014; Werling and Geschwind 2013). The current study also moved alongside debates over whether the current diagnostic protocols and measures for diagnosing ASD are 'male biased' and reports that some women with HFA are not being diagnosed early enough (Gould and Ashton-Smith 2011; Hiller et al. 2015; Mandy et al. 2012).

The findings corroborate suggestions that women with HFA are frequently camouflaging their difficulties and outwardly presenting as socially skilled (Autism In Pink 2014; Kopp and Gillberg 1992; Müller, Schuler and Yates 2008). Rich qualitative information provided insight into *how* women might be achieving this, by relying on others, camouflaging, or dropping the pretence by being more honest and open. To date, choosing to opt out from attempts to conceal limitations has perhaps not received much attention as a potential core strategy in anecdotal accounts and highlights the variation between individuals. This diversity in coping approaches could provide vital clues regarding how females accommodate to their difficulties over time.

Clinical & Research Implications

The narratives explored by this study bring to light the extraordinary and extensive efforts of women with HFA, their individual strengths, and level of determination. However, the illustrated potential for negative outcomes such as physical and emotional exhaustion and

being misunderstood by others, adds to the imperative for an earlier diagnosis to provide opportunities to support this group of females. Unfortunately, the fact that the participants had only recently been diagnosed in adulthood, and in several cases reported misdiagnosis, emphasised how early openings to support them may have been missed. Ironically, the ardent use of strategies to camouflage social limitations may have allowed less visible social difficulties to be missed, or overlooked by others, as suggested in previous research (Harrop et al. 2015; Hiller et al. 2015).

Various authors have mentioned the complications associated with looking for signs and symptoms of HFA in females, who on the surface seem to be managing well (Aggarwal and Angus 2015; Attwood 2007; Dworzynski et al. 2012; Gould and Ashton-Smith 2011). If females with HFA appear to be successfully hiding skills deficits, the onus seems to be on the family, health and educational systems to be better informed of: *(a)* how autism can present across the spectrum and between males and females; *(b)* and how females with HFA can experience and respond to social environments. Those entrusted with making diagnostic decisions could learn from like accounts and be mindful of the need to ask or observe in greater detail what strategies an individual might be using and why, to help them uncover potential difficulties. As the narratives show, irrespective of strategy or no strategy, adverse consequences can arise. Further research is needed to outline what interventions might be most helpful not only to address the lack of skill, but to also facilitate adjustment when things go wrong.

It is noteworthy to reflect on the fact that neuro-typical women may also use some of the social strategies used by the women in this study, potentially due to their own perceived pressures from society to be empathetic and sociable. It would be useful to compare the two groups of females to further assess the functions behind the use of such strategies.

Even though this research has focused on the female experience, it is important to mention that qualitative studies on this theme have rarely examined what strategies males with HFA might be using. It is possible that males with HFA may be equally aware of the need to fit in and are also using various methods to do so. Clearly, knowledge and understanding of autism is a growing field and time needs to be invested in exploring the lived experience of all individuals who are high-functioning, so that society can start providing the support they need.

The qualitative data arising from this study also provided a rich source of relevant material that was beyond the scope of this paper. Participants spoke about the positive and negative impacts of receiving a diagnosis in adulthood; feeling lonely and unaccepted in a neuro-typical world; feeling crippled by empathy and feeling emotions deeply; and how school was a living nightmare. To do justice to the themes raised, it is hoped that further analysis will follow.

Author Contributions: AH conceived of the study, participated in its design and co-ordination, performed the qualitative analysis, and drafted the manuscript. KC participated in the qualitative analysis and helped to draft the manuscript. Both authors read and approved the final manuscript.

Compliance with Ethical Standards

This article does not contain any studies with animals performed by any of the authors.

Ethical approval: All procedures performed in this study involving human participants were in accordance with the ethical standards of the institutional and national research committees and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent: Informed consent was obtained from all individual participants included in this study.

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Appendices

Appendix A

Table 1

Participant Demographics

Participant	Age	Years Since Diagnosis	Nationality	Ethnicity	Marital Status	Children	Occupation
1	59	1	British	White	N/C	Y	N/C
2	49	3	British- Cypriot	White- Other	Married	N	Self-Employed
3	21	1	British	White	Single	N	Student
4	28	1	British	White	Single	N	Volunteering
5	32	3	British	White	Married	Y	Retail Assistant
6	21	1	British	White	Co-habiting	N	Student
7	36	1	British	White	Married	Y	Support Worker
8	47	3	British	White	Single	Y	CEO
9	44	2	British	White	Married	Y	Administrator
10	50	1	British	White	Single	N	Retired
11	31	0	British	White	Married	N	Social Worker

Abbreviations. N/C = No Comment; N = No; Y = Yes

Appendix B

Table 2

Theme Definitions

Theme	Definition
The Struggle To Understand The Intricacies Of Social Etiquette	Considerable difficulties being aware of and understanding others' social behaviour and social expectations, and how one should behave in social events in line with social norms. This led some women to feel clueless and/or make mistakes in social situations.
Trying To Fit In – Keeping Your Challenges Quiet	Experiencing difficulties understanding the intricacies of social etiquette led some women to want to hide their social difficulties from others by trying to superficially present as socially skilled. They would put on a social act and use certain physical or cognitive social strategies (before, during or after social situations), to avoid making social mistakes, presenting as socially inept, or being judged by others.
I Am Who I Am – Being Open And Honest	Some women chose to manage their social difficulties by being themselves in social situations rather than trying to fit in or keep their challenges quiet. They did so through openness and honesty in their social behaviours, by dropping previously used social acts, and generally being true to themselves as an individual. Some did so regardless of what others may think or feel.
Relying On Others In Social Situations	Many of the women relied on others (i.e. friends, partners, family members) from childhood through to adulthood to support them in social contexts, who acted as a social guide or rescuer. This helped with reducing feelings of social anxiety or inadequacy, for avoiding making social mistakes, for indirect or direct cues of how to behave in a social context, or for avoid social situations altogether.
Strategies Or No Strategies – It All Has An Effect	Despite whether or not the women used social strategies (and for whatever reason) due to common difficulties in understanding the social world, the women reported more negative, than positive outcomes.

Appendix C

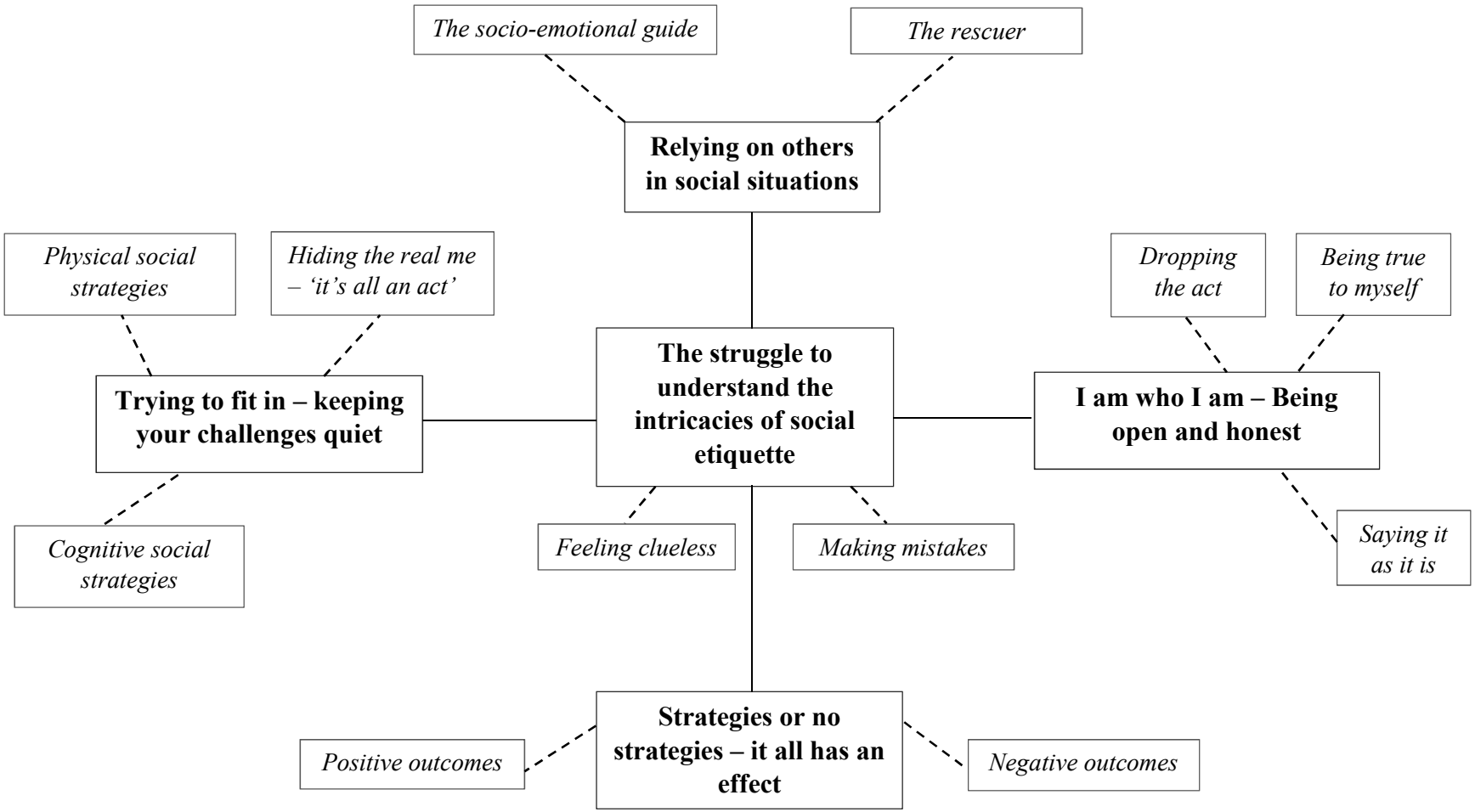

Fig. 1 Final Thematic Map

Appendix D

Table 3

Thematic Table: Overview of Themes

Theme *(Frequency)*	Sub-themes *(Frequency)*	Codes	Example Quote *(Participant; Transcript Line Numbers)*
Overarching Theme: The Struggle To Understand The Intricacies Of Social Etiquette *(N=8)*	Feeling clueless *(n=7)*	▪ Feeling clueless in social situations	"When I was at school…some people say things like oh he fancies her you can tell how he's looking at her and I'd say how can you tell, she would just start laughing…Me not having a clue what was going on most of the time…I haven't got a clue what they're going on about…" *(P10; 151-165)*
	Making mistakes *(n=5)*	▪ Making mistakes in social situations	"…they said what do you say and I said please thank you sorry that's all of them……I wasn't sure what you're meant to say…so like I just went with all of them just in case" (*P3; 347-351)*
Theme 2: Trying To Fit In – Keeping Your Challenges Quiet *(N=11)*	Hiding the real me – it's all an act *(n=9)*	▪ Becoming a fictional character ▪ Mimicking others in social situations ▪ Trying to blend in/ Go unnoticed ▪ Putting on a social act/ wearing a mask ▪ Being a social butterfly	"…my mum, my brother, my kids, my husband, my friends, and for each one of them people I was a different person. I was what they wanted me to be…no matter what I did I was having to put an act on all the time..." *(P8; 203-214)*

Theme *(Frequency)*	Sub-themes *(Frequency)*	Codes	Example Quote *(Participant; Transcript Line Numbers)*
		▪ Tempering own behaviours/ difficulties to meet social expectations	
	Physical social strategies *(n=8)*	▪ Learning social skills from online resources ▪ Social avoidance ▪ Keeping busy/ distracting self in social situations ▪ Pacing to avoid social exhaustion ▪ Eye contact strategies help ▪ Easier to communicate and express self in written form (i.e. on paper; online; etc) ▪ Looking for cues/ signs ▪ Reducing sensory stimulation in social situations	"…when my sister got married, I preferred with all my kids to decorate all the hall for her. I made the wedding cake and all the wedding veil and everything and I organised cutting the cake. That's what I like to do…I think the last one…I didn't make the cake I ended up serving the cake. I'm better at doing things at parties…they're all out at the party, they're all dealing with it and I can stand back…" *(P1; 42-47)*

Theme *(Frequency)*	Sub-themes *(Frequency)*	Codes	Example Quote *(Participant; Transcript Line Numbers)*
	Cognitive social strategies *(n=10)*	▪ The high importance of sharing a common interest for success in social situations ▪ Being prepared/ organised in advance helps in social situations ▪ Doing little mental checks ▪ Hypervigilant overthinking brain in social situations ▪ Double checking meanings/ asking questions to aid social understanding ▪ Using logic to interpret and respond to social situations	"...I'll sometimes think no I need to stop now and give the person a chance to talk, so like a little mental check that I need to kind of stop and listen…" (*P11; 289-290)*
Theme 3: I Am Who I Am – Being Open And Honest *(N=9)*	Being true to myself *(n=7)*	▪ Just being me ▪ Mimicking/ acting is not my style	"…I just tell them to bugger off it's my life…I don't really care what people think of me…I am who I am…you're still the same you…you're still the same person…" *(P4; 164-390)*

Theme *(Frequency)*	Sub-themes *(Frequency)*	Codes	Example Quote *(Participant; Transcript Line Numbers)*
		▪ Going with my gut instincts in social situations	
	Dropping the act *(n=2)*	▪ Dropping the social 'act'/ 'mask'/ 'blending'	"…no matter what I did I was having to put an act on all the time…so I just stopped…" *(P8; 214-221)*
	Saying it as it is *(n= 6)*	▪ Automatic response/ Preference in social situations is to be honest	"My automatic response in most social situations is to be honest …If you ask me do you like me you would get the truth…" *(P2; 39-249)*
Theme 4: Relying On Others In Social Situations *(N=8)*	The socio-emotional guide *(n=8)*	▪ Being told what to say or do by others in social situations	"…I've got a large family…they're still asking and it makes me embarrassed…my dad usually says to me just say hello and walk on and that's what he said and I do that I just go hi and I walk on…" *(P4; 197-200)*
	The rescuer *(n=5)*	▪ Being rescued by others in social situations	"…in the early stages I found she was stepping in quite a lot to speak for me to explain for me…it was clear that I wasn't understanding what I was saying and she was getting really frustrated with me and then this other girl would be kind of like well, but 'what she means is this right'…" (*P7; 160-163)*

Theme *(Frequency)*	Sub-themes *(Frequency)*	Codes	Example Quote *(Participant; Transcript Line Numbers)*
Theme 5: Strategies Or No Strategies – It All Has An Effect *(N=9)*	Negative outcomes *(n=9)*	▪ Social exhaustion ▪ Anticipatory anxiety before social events ▪ Sometimes my strategies just don't work ▪ Being misunderstood in social situations ▪ Social 'meltdown(s)'	"…I'll be thinking about all of that at the same time as having a conversation with someone so I will get social exhaustion at the end of the day…" (*P11; 466-467)*
	Positive outcomes *(n=2)*	▪ Strategies becoming more natural behaviour with practice ▪ Learning social skills through experience	"…it's like you've got to learn it's not instinctive. I've been around a long time so I've figured things like that…you see that then you learn to do this…I tend to take literally what I've learnt over the years that's what you say…" (*P10; 268-280)*

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This research was supported by the North Wales Clinical Psychology Programme at Bangor University, North Wales, and completed as part of a Doctorate in Clinical Psychology. The author remains at affiliation to date.

The researcher AH would like to thank the participants who kindly took part in the study, and co-author KC and the recruiting professionals for their assistance and support.

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Section Four:

Contributions to Theory and Clinical Practice

Summary of Outcomes

Review findings. The systematic review advocated that young males and females aged 0–18 years old may be more similar than dissimilar in the severity of their core Autism Spectrum Disorder (ASD) symptomatology, which supports previous findings (e.g. Holtmann et al., 2007; Horovitz et al., 2011; Pilowsky et al., 1998). However, the review reinforced previous suggestions that young males and females may differ with regards to the nature and quality of their repetitive and restrictive behaviours, interests and activities (RRBIs) (Hattier et al., 2011; Lai et al., 2011; Szatmari et al., 2012), whereby young females' interests tend to be more stereotypically female. Other potential gender differences were highlighted for the co-morbidity of other conditions; sensory sensitivity and parental distress levels; and ASD-specific neurobiological differences in the brain. The findings for cognitive functioning and externalising behaviours were mixed. Overall, the review corroborated and updated previous evaluations, with similar limitations and biases observed. Consistent with previous reviews, the current findings point to the need for further studies addressing the noted limitations in the field.

Empirical findings. The empirical study conducted a thematic analysis of eleven semi-structured interviews of women with high-functioning autism (HFA), to explore whether or not they camouflaged their social limitations, and if so, what strategies they used in order to do so. Results indicated that the women experienced difficulties understanding social etiquette and would make mistakes. Some women did camouflage, others dropped the attempt and others did not see a need to mask their difficulties. The analysis shed light on the type of approaches used when hiding, or compensating for deficits, and the reasons why some women chose to be more open and honest. Interestingly, regardless of whether or not the women tried to cover over their difficulties, they seemed to rely heavily on significant others

for support. Regrettably, more negative outcomes than positive from their social experiences were commented upon.

Overall summary. The above papers suggest not only that there may be differences in how males and females with HFA present to others and experience life, but also validate the view that there may be a differing female phenotype (i.e. tendencies) within HFA (Lai, Lombardo, Auyeung, Chakrabarti, & Baron-Cohen, 2015). Improved understanding of gender differences in autism and of the proposed HFA female phenotype, might help to provide reasons as to why some females on the spectrum are missed, misdiagnosed or diagnosed later on in life. In order to move forward, higher quality quantitative research as well as more qualitative research exploring the lived experience of individuals with HFA, is required. Until the evidence base is strengthened, clinical, research and educational professionals and individuals with autism are advised to continue to view the available literature with caution.

Implications for Future Research

The limitations cycle. Various limitations and biases across the research literature are noted by the current and previous reviews (e.g. Lai et al., 2015; Rivet & Matson, 2011; Rubenstein, Wiggins, & Lee, 2015), such as small sample sizes, variability in study design and the measures used, fewer female participants, a lack of comparison to matched typically developing (TD) controls, and poor generalisability. When looking in detail at these issues, the most common caveat is that of an unbalanced gender representation due to recruiting fewer females. Some researchers argue that this is due to lower prevalence rates of autism in females, due to the ‘female protective effect’ (Jacquemont et al., 2014; Robinson et al., 2013). However, emerging evidence is gaining pace which suggests that the commonly reported gender ratio of 4:1 may be inaccurate with more females in society with autism than

originally perceived, which could possibly be due to a differing female phenotype in HFA (Lai et al., 2015; Rubenstein et al., 2015; Van Wijngaarden-Cremers et al., 2014). Some argue that this gender ratio inaccuracy is due to an inherent male-bias in our understanding of autism and the diagnostic criteria and assessment tools used (Goldman, 2013; Kirkovski et al., 2013; Wilkinson, 2008).

It is therefore possible that a limitations cycle is being perpetuated within the evidence base, whereby fewer females are being enrolled in studies due to clinical and diagnostic biases. As a result less is potentially known about whether males and females with autism significantly differ, and whether there actually is a female phenotype in HFA. Until the potential male-bias in the diagnostic process is addressed and more is known about females with autism and those who are being missed are ascertained, the dilemma will remain.

Future research. Replication of this study with men with HFA would be of interest, to explore if they might also camouflage in social situations, and if so whether they employ similar strategies to women. One would also be curious to explore whether there are males with HFA who similarly choose not to mask difficulties, and whether the outcomes in general concur with the female experience. Without further qualitative research of this nature we do not know if the findings in this study are unique to adult females. It would also be interesting to replicate the current study with a younger school-aged male and female cohort aged 6–18 years old, to assess whether gender differences in social coping methods occur in this cohort with time. Further research exploring the possibility of a female phenotype in HFA may also wish to investigate the cognitive, behavioural, social and biological mechanisms behind the use of strategies to either camouflage or not in social situations, potentially incorporating neuroimaging technology into the methodology.

Implications for Theory Development

To date, little has been proposed regarding a theoretical model for a female phenotype in HFA, but interest in this subject seems to be moving swiftly forward (Aggarwal & Angus, 2015; Cridland, Jones, Caputi, & Magee, 2014; Halladay et al., 2015). In line with previous research and theories of autism it would seem reasonable to suggest a tentative hypothetical model, underpinned by current findings for a differing female phenotype in HFA that builds upon previously presented suggestions (Lai et al., 2015; Rubenstein et al., 2015; Van Wijngaarden-Cremers et al., 2014; Werling & Geschwind, 2013.

Proposed model. As a result of my research, I propose a model of a female phenotype in HFA that consists of two differing subtypes that share five common tendencies (see Figure 1; Appendix A). Most females would fit into one of the two proposed subtypes, '*Type A*' or '*Type B*'. Some may move from one subtype to the other if they change their coping approach. Type A represents a sub-group of females with HFA who use social strategies to mask and compensate for their autistic behaviours and social skills limitations. Type B represents a sub-group of females with HFA who do *not* use strategies to conceal their social difficulties or autistic behaviours, but who use methods which promote being open, honest and true to themselves.

The tendencies purported to be common between these two subtypes include: fewer externalising behaviours (Baker & Milivojevich, 2013; Hiller, Young, & Weber, 2014; Presmanes-Hill et al., 2014); fewer RRBIs with stereotypically female interests (Frazier, Georgiades, Bishop, & Hardan, 2014; Hiller, Young, & Weber, 2015); increased internalised behavioural difficulties (i.e. social exhaustion, anxiety or low mood) (Gadow & DeVincent, 2012; Mandy et al., 2012; May, Cornish, & Rinehart, 2014; Solomon et al., 2012); and

support from others who act as a socio-emotional guide and/or rescuer in social contexts (Figure 1; Appendix A).

Alongside this model, various mechanisms underpinning each subtype will now be proposed as it is a possibility that the mechanisms behind tendencies to camouflage or not in social situations differ (see Table 1; Appendix B).

In line with previous findings, the key mechanisms underpinning the subtype A female's methods to camouflage could include: (a) increased levels of self-awareness as compared to subtype B females (Lai et al., 2011); (b) increased social motivation compared to subtype B females (Chevallier et al., 2011; Head et al., 2014; Hiller et al., 2015; Kopp & Gillberg, 1992); (c) mentalizing capabilities for first order belief attributions (Baron-Cohen, 2006); and (d) reduced brain masculinisation as compared to subtype B individuals, yet more masculinised than TD females (Alaerts, Swinnen, & Wenderoth, 2016; Auyeung et al., 2009; Baron-Cohen, 2002; Baron-Cohen, Lutchmaya, & Knickmeyer, 2004; Bejerot et al., 2012; Lombardo et al., 2012).

Previous research supporting the Theory of Mind hypothesis has suggested that individuals with HFA *can* develop mentalizing skills, but later on in development and not at as complex a level as TD peers (i.e. second order belief attributions) (Baron-Cohen, 1995, 2002, 2006; Brent at al., 2004; Chevallier et al., 2010). Subtype A females in the current empirical study reported using strategies to 'blend in' and go unnoticed, due to fears of being negatively judged by others in society. In comparison, subtype B females reported forgetting to think of others' feelings in social interactions or reported saying things without sensitivity regardless of the social or personal consequences. Therefore, it is possible that subtype A females have mentalizing capabilities for first order attributions (i.e. 'they are thinking I

am…') (Baron-Cohen, 2006) and that subtype B females may have reduced mentalizing abilities for first-order belief attributions.

Subtype A females may also feel more social pressure to engage in behaviours aimed at trying to appear neuro-typical. In contrast to social motivation theories of autism (Chevallier et al., 2011), Subtype A females also reported wanting to fit in and be accepted by society and befriended by others, which could be explained by higher levels of social motivation and self-awareness as compared to subtype B females, who may have lower levels of self-awareness of social motivation (Chevallier et al., 2011; Head et al., 2014; Hill, 2004; Hiller et al., 2015; Lai et al., 2011). Subtype A females could possibly experience less executive dysfunction than subtype B females (Hill, 2004; Ozonoff, 1997; Russel, 2002), affording them better self-monitoring, planning or multi-tasking abilities, or increased inhibition, of which all could be potentially useful skills for social camouflage.

There may also be differences in the neurobiological and genetic mechanisms underlying differing social strategy use, which themselves implicate differences in the degree of masculinisation occurring in the female HFA brain. For example, there is evidence to suggest that females with HFA have a hyper-masculinised brain similar to that of TD males (Alaerts et al., 2016), which has previously been linked with increased testosterone levels (Ingudomnukul, Baron-Cohen, Wheelwright, & Knickmeyer, 2007) and reduced neural connectivity and increased dysfunction in certain areas of the brain believed to be responsible for social communication and interaction and executive functioning capabilities (Hill, 2004; Lombardo et al., 2012; Raine et al., 2011; Sparks et al., 2002). It is a possibility that subtype A females may have a hypo-masculinised brain, contrary to the extreme male brain (EMB) theory of autism (Baron-Cohen, 2002). In contrast, subtype B females may have a hyper-masculinised brain, thus supporting the EMB theory.

Finally, it is important to note that an individual's life experiences, personality, surrounding cultural and social norms, as well as other potential variables currently beyond the scope of this paper, could also underpin the use or non-use of certain strategies in the social arena. In order to establish whether the proposed model, subtypes and mechanisms regarding a potential female phenotype in HFA are valid, further exploratory research is required that attempts to incorporate neuroimaging technology and behavioural observations, across differing social contexts, into their methodology.

Implications for Clinical Practice

The diagnosis dilemma. The findings from the current review and empirical study highlight the potential difficulties that professionals may face in deciding whether or not an assessment is warranted for a female (particularly those with average or above intelligence), and if so, whether or not she meets the diagnostic criteria for ASD (of milder severity) or Asperger syndrome.

Diagnosticians are inherently faced with various obstacles, the first being that there may be a female phenotype in HFA which professionals may not be aware of or experienced in, thus preventing some females from being diagnosed. The second obstacle for professionals is the possibility that the current assessment tools and diagnostic criteria may be male biased. If this is the case, then it is arguable that a male stereotyped understanding of autism, alongside cultural, social and individual influences, could potentially miss a large number of females. Resultantly one may argue that clinicians may only see what they expect or believe to see. Thirdly, clinicians may want to consider the influence of social contexts upon the individuals' and their own behaviours.

Although previous attempts have been made to create assessment tools which are more geared towards assessing females with HFA, such as the Autism Spectrum Screening

Questionnaire-Revised Extended Version (ASSQ-REV; Kopp & Gillberg, 2011), certain limitations and biases remain with regards to the external and internal validity of such measures. This currently puts their clinical use into question. As such, further updates and redevelopments of the currently available assessment tools are required, and it would be vital to involve females with HFA in these efforts.

In light of the aforementioned obstacles, it would be important for clinicians to not only stay abreast of the current literature, but to also directly enquire with females referred for an assessment whether they camouflage or not and to explore the function and intensity of their specific interests and hobbies.

The wellbeing of females with HFA. The findings from the current review and empirical paper suggest that females with HFA may be experiencing anxiety, low mood, social exhaustion, interpersonal conflict, being misunderstood by others, fears of being judged by others, and may be significantly affected by the loss of a socio-emotional guide. All of these difficulties could have a detrimental impact on their overall quality of life, specifically their emotional and physical wellbeing and interpersonal relationships. This implies that females with HFA may be at an increased risk of experiencing mental health difficulties and may require additional support. This highlights the need for mental health professionals working in primary and secondary care to be further trained in ASD. They may also need to consider the possibility of and look out for an undiagnosed ASD, particularly when assessing a high-functioning female referred to their service for ill mental health.

Improving professional practice, interventions and support services. The findings also draw attention to the importance for local governmental policies, strategies and national incentives to remain equally informed of the evidence base, and to ensure that they are referencing up to date prevalence rates and evidence-based knowledge. This is particularly

important if it is highlighted that the commonly cited 4:1 gender ratio is questionable for high-functioning individuals on the spectrum. This is important when considering how policies often inform the allocation of funds for services.

The findings also highlight the importance of ensuring significant others, including educational professionals and employment agencies, who act as socio-emotional guides for females with HFA, receive adequate levels of support and training. Increased awareness may lead to more young high-functioning girls with autism being identified during childhood or adolescence.

Finally, the knowledge garnered from the current empirical study may be useful for informing the content of social skills interventions available to girls and women with HFA, and there may be a need for all-female HFA support groups for those who wish to share their experiences with others.

Personal Reflections

The reflective process is an important component of qualitative research due to an acknowledgement that the researcher's own values, beliefs, ethnicity, culture and previous experiences will all shape how they interpret and view their own scientific practice. Throughout the study the researcher kept a reflective diary to note down thoughts, feelings and observations, in vivo.

One of the key observations concerned the social construction of femininity and the sharing of a feminine identity. On one hand the researcher noted that she shared a female identity with the participants, reflecting on her own concept of what it means to be a woman in a western society, and reflecting further on the gender debate in ASD research with regards to differences in interpretations and use of the terms 'gender' and 'sex'. The

researcher also wondered whether similar narratives would have been shared if the researcher were male, and how participants might have felt and reacted if interviewed by a man.

In connection with this notion of femininity and shared identity, the researcher also felt like a neuro-typical outsider, who would never truly understand and appreciate what it means to be a woman with HFA. At times the researcher felt uncomfortable when participants reflected on how society views and treats individuals on the autistic spectrum, often judged for not fitting into society's stereotypical view of what it means to be a socially active member of society. Our own cultural norms and social expectations appeared to greatly impact on the lives of the women, and the researcher noted how at times she felt uncomfortable or angry at hearing how some of the women had been treated by others.

Another of the key observations was that of the researcher's own anxiety throughout various stages of the project, particularly during the recruitment, interview, analysis and write-up stages. Due to the high importance of the study in relation to the researcher's own training and qualification to become a clinical psychologist, each of the aforementioned stages were often anxiety provoking for the researcher. The researcher observed being fused with thoughts about something going wrong during an interview, certain documents not being accurate, not being experienced in thematic analysis, and so on. These anxieties were at times helpful as they gave the researcher motivation to work hard and complete each phase of the project, but at times increased the researcher's stress levels.

An additional reflection involved the researcher's experience of having to discard irrelevant codes during the analysis process, and concerns around doing a disservice to the stories shared. On the one hand the researcher wanted to keep all of the codes which were of importance to the women interviewed. Some of these codes were extremely interesting and contained valuable knowledge that the researcher was keen to share with others. On the other

hand, the researcher appreciated the importance of staying true to the original research question and that having to discard irrelevant codes is an expected procedure during thematic analysis. The researcher took these reflections to the research supervisor, and discussions were held around being able to balance one's own anxieties around pleasing others and doing justice to the stories shared with needing to complete a strong piece of high-quality research. The researcher and supervisor jointly agreed that the discarded information would be suitable for future papers.

The final reflection noted by the researcher during the interview process was that of conflictual admiration and fatigue. The researcher admired the women for meeting up with a professional who they had not met before and yet were so open and willing in telling their personal stories in the hope that this information may be helpful to others. However, the researcher also at times felt physically fatigued, not just due to the effortful nature of qualitative research, but due to the tendency for some of the participants to talk at length at a very fast pace about a particular topic. On these occasions it was hard for the researcher to remain in the present moment and respond effectively. The researcher also felt emotionally fatigued following the interviews due to the often emotive nature of the experiences being shared.

Despite the aforementioned reflections, the researcher truly enjoyed meeting all of the women who participated in the study, hearing their stories and having the additional privilege of being able to learn and develop on both a personal and professional level.

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Appendices

Appendix A

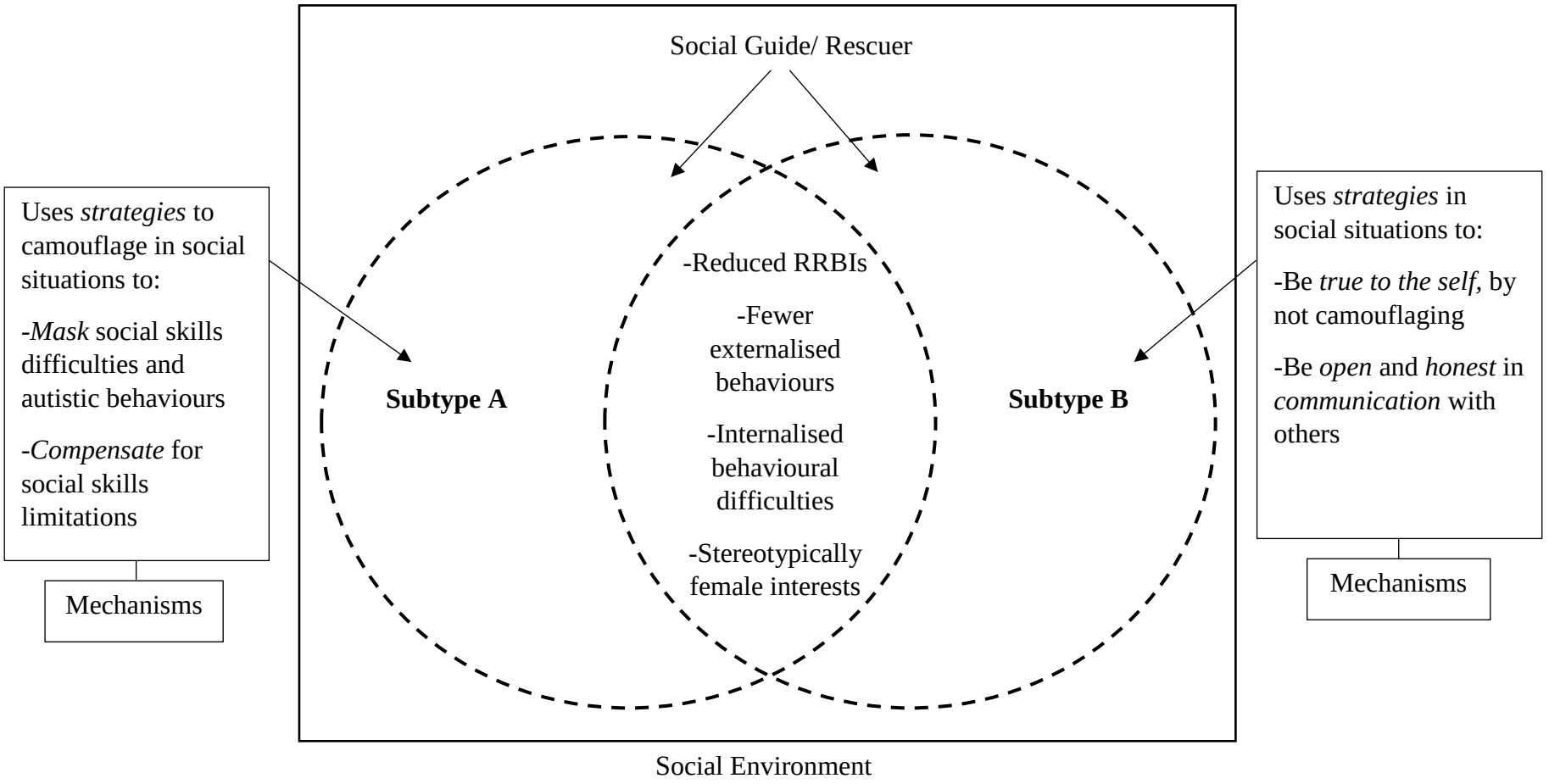

Figure 1. Proposed model of female phenotype in high-functioning autism

Note. RRBIs = Repetitive and restrictive behaviours, interests and activities

Appendix B

Table 1

Hypothesised mechanisms underpinning differing subtypes A & B

Subtype A Mechanisms	Subtype B Mechanisms
▪ Increased self-awareness	▪ Reduced self-awareness
▪ Increased social motivation	▪ Diminished social motivation
▪ Increased executive functioning	▪ Impaired executive functioning
▪ Mentalizing capabilities[1]	▪ Reduced mentalizing capabilities[1]
▪ Hypo-masculinised brain	▪ Hyper-masculinised brain
▪ Individual experiences	▪ Individual experiences
▪ Personality traits (i.e. introvert)	▪ Personality traits (i.e. extrovert)
▪ Social environment	▪ Social environment
▪ Cultural & social norms	▪ Cultural & social norms

Note. [1] = For first order belief attributions

Section Five:
Ethics Appendices

Appendix A: Bangor University Liability Insurance Confirmation

Hasilwood House
60 Bishopsgate
London EC2N 4AW
Tel: 020 7847 8670
Fax: 020 7847 8689

TO WHOM IT MAY CONCERN

1 August 2014

Dear Sir/Madam

BANGOR UNIVERSITY
AND ALL ITS SUBSIDIARY COMPANIES

We confirm that the above Institution is a Member of U.M. Association Limited, and that the following covers are currently in place:-

1. **EMPLOYERS' LIABILITY**

Certificate No.	Y016458QBE0114A/026
Period of Cover	1 August 2014 to 31 July 2015
Limit of Indemnity	£25,000,000 any one event unlimited in the aggregate.
Includes	Indemnity to Principals
Cover provided by	QBE Insurance (Europe) Limited and Excess Insurers.

2. **PUBLIC AND PRODUCTS LIABILITY**

Certificate of Entry No.	UM026/95
Period of Cover	1 August 2014 to 31 July 2015
Includes	Indemnity to Principals
Limit Of Indemnity	£50,000,000 any one event and in the aggregate in respect of Products Liability and unlimited in the aggregate in respect of Public Liability.
Cover provided by	U.M. Association Limited and Excess Cover Providers led by QBE Insurance (Europe) Limited

If you have any queries in respect of the above details, please do not hesitate to contact us.

Yours faithfully

Susan Wilkinson
For U.M. Association Limited

ISO 9001
REGISTERED FIRM

Appendix B: School of Psychology Ethical Approval

From: Everil McQuarrie
Sent: Tuesday, 31 March 2015 13:58
To: Aimee Jane Hooper

Dear Aimee,

2015-14949 A qualitative study looking at the strategies that adult higher functioning women on the autistic spectrum report in order to compensate for and 'mask' social skills deficits.

Your research proposal number 2015-14949
has been reviewed by the Psychology Ethics and Research Committee
and the committee are now able to confirm ethical and governance approval for the above research on the basis described in the application form, protocol and supporting documentation. This approval lasts for a maximum of three years from this date.

Ethical approval is granted for the study as it was explicitly described in the application

If you wish to make any non-trivial modifications to the research project, please submit an amendment form to the committee, and copies of any of the original documents reviewed which have been altered as a result of the amendment. Please also inform the committee immediately if participants experience any unanticipated harm as a result of taking part in your research, or if any adverse reactions are reported in subsequent literature using the same technique elsewhere.

Appendix C: NHS Ethics Proposal: Initial IRAS Form

Full Set of Project Data IRAS Version 3.5

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please enter a short title for this project (maximum 70 characters)
Investigating the masking of social skills deficits in female Autism 1

1. Is your project research?

(●) Yes ( ) No

2. Select one category from the list below:

( ) Clinical trial of an investigational medicinal product
( ) Clinical investigation or other study of a medical device
( ) Combined trial of an investigational medicinal product and an investigational medical device
( ) Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice
( ) Basic science study involving procedures with human participants
( ) Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology
(●) Study involving qualitative methods only
( ) Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)
( ) Study limited to working with data (specific project only)
( ) Research tissue bank
( ) Research database

If your work does not fit any of these categories, select the option below:

( ) Other study

2a. Please answer the following question(s):

a) Does the study involve the use of any ionising radiation?	( ) Yes	(●) No
b) Will you be taking new human tissue samples (or other human biological samples)?	( ) Yes	(●) No
c) Will you be using existing human tissue samples (or other human biological samples)?	( ) Yes	(●) No

3. In which countries of the UK will the research sites be located? *(Tick all that apply)*

[ ] England
[ ] Scotland
[x] Wales
[ ] Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

- ○ England
- ○ Scotland
- ◉ Wales
- ○ Northern Ireland
- ○ This study does not involve the NHS

4. Which review bodies are you applying to?

- ☑ NHS/HSC Research and Development offices
- ☐ Social Care Research Ethics Committee
- ☑ Research Ethics Committee
- ☐ National Information Governance Board for Health and Social Care (NIGB)
- ☐ National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D offices, the CI must create Site-Specific Information Forms for each site, in addition to the study-wide forms, and transfer them to the PIs or local collaborators.

5. Will any research sites in this study be NHS organisations?

◉ Yes ○ No

6. Do you plan to include any participants who are children?

○ Yes ◉ No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

○ Yes ◉ No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the NIGB Ethics and Confidentiality Committee to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

○ Yes ◉ No

9. Is the study or any part of it being undertaken as an educational project?

◉ Yes ○ No

Please describe briefly the involvement of the student(s):
The student is a trainee Clinical Psychologist who is conducting the research (interviews with the participants and qualitative analysis of the interview content) for her third year research project/thesis in order to qualify as a clinical psychologist.

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

◉ Yes ○ No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

○ Yes ◉ No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

○ Yes ◉ No

Full Set of Project Data IRAS Version 3.5

Integrated Research Application System
Application Form for Research involving qualitative methods only

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting Help.

Please define any terms or acronyms that might not be familar to lay reviewers of the application.

Short title and version number: (maximum 70 characters - this will be inserted as header on all forms)
Investigating the masking of social skills deficits in female Autism 1

PART A: Core study information

1. ADMINISTRATIVE DETAILS

A1. Full title of the research:

A qualitative study looking at the strategies that adult higher functioning women on the autistic spectrum report in order to compensate for and 'mask' social skills deficits.

A2-1. Educational projects

Name and contact details of student(s):

Student 1

Title	Forename/Initials	Surname
Mrs	Aimee Jane	Hooper

Address: Llys Owen, Maes Ogwen, Tregarth, Bangor, Gwynedd, North Wales

Post Code: LL57 4PH
E-mail: psp2ce@bangor.ac.uk
Telephone: 07826062415
Fax:

Give details of the educational course or degree for which this research is being undertaken:
Name and level of course/ degree:
Doctorate in Clinical Psychology (DClinPsy)

Name of educational establishment:
Bangor University, North Wales

Name and contact details of academic supervisor(s):

Academic supervisor 1

Title	Forename/Initials	Surname
Dr	Kristina	Cole

Address: Roslin CMHT, Nant y Gamar Road

	Craig y Don, Llandudno, Conwy
Post Code	LL30 1YE
E-mail	kristina.cole@wales.nhs.uk
Telephone	01492 860926
Fax	

Please state which academic supervisor(s) has responsibility for which student(s):
Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.

Student(s)	Academic supervisor(s)
Student 1 Mrs Aimee Jane Hooper	☑ Dr Kristina Cole

A copy of a current CV for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.

A2-2. Who will act as Chief Investigator for this study?

- (•) Student
- ( ) Academic supervisor
- ( ) Other

A3-1. Chief Investigator:

Title	Forename/Initials	Surname
Mrs	Aimee Jane	Hooper

Post	Trainee Clinical Psychologist
Qualifications	BSc Applied Psychology of First Class Honours
Employer	North Wales Clinical Psychology Programme & BCUHB
Work Address	School of Psychology, Brigantia Building, Bangor University, Bangor, Gwynedd North Wales
Post Code	LL57 2DG
Work E-mail	psp2ce@bangor.ac.uk
* Personal E-mail	
Work Telephone	01248 388365
* Personal Telephone/Mobile	07826062415
Fax	

** This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.*
A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.

A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?
This contact will receive copies of all correspondence from REC and R&D reviewers that is sent to the CI.

Title	Forename/Initials	Surname
Mr	Hefin	Francis

Address	School of Psychology Bangor University, Bangor, Gwynedd
Post Code	LL7 2AS
E-mail	h.francis@bangor.ac.uk
Telephone	01248388339
Fax	

A5-1. Research reference numbers. *Please give any relevant references for your study:*

Applicant's/organisation's own reference number, e.g. R & D (if available):

Sponsor's/protocol number:

Protocol Version:

Protocol Date:

Funder's reference number:

Project website:

Additional reference number(s):

Ref.Number Description	Reference Number

Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you have registered your study please give details in the "Additional reference number(s)" section.

A5-2. Is this application linked to a previous study or another current application?

○ Yes ◉ No

Please give brief details and reference numbers.

2. OVERVIEW OF THE RESEARCH

To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.

A6-1. Summary of the study. *Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, this summary will be published on the website of the National Research Ethics Service following the ethical review.*

The purpose of the current study is to address a much needed area of research by attempting to answer the following question:
1. What strategies and techniques may females with higher functioning Autism (HFA) be using in order to mask their social skills deficits in the social arena, and when, how and why might they do this?

In attempting to answer this question, we would aid our understanding of the female phenotype in HFA and reduce the previous tendency toward a 'male biased' understanding of Autism. The information gained could also inform on how modify current assessment tools to reduce the risk of possible under or misdiagnosis, and ensure earlier diagnoses for females to aid access to support.

One group of English speaking female adults (N = 8) with a diagnosis of HFA will be recruited, aged 19-60 years, without any language impairment or intellectual disability.

The consenting participants will be invited to a semi structured interview with the researcher at a mutually agreed day and time at a set location, lasting for approximately 60-80 minutes. Participants will be asked questions with prompts if required.

The interviews will take place at Bangor University or the Roslin Community Mental Health Team base, dependent upon the participants' ability to travel and the distance of their home or work address from Bangor University.

Due to the qualitative nature of the interview data, the transcribed interviews will be analysed using the qualitative method of Applied Thematic Analysis (ATA; Guest, MacQueen & Namey, 2012). ATA is highly credible and would allow the trainee to identify and examine themes from the interviews.

A6-2. Summary of main issues. *Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.*

Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, R&D office or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.

Risk to participants

The likely problematic aspects to arise may be in participants feeling uncomfortable in being audio-taped during the interview. This will require audio consent and confidentiality forms to be signed by the participant and researcher before commencing the interview, in order to allow the researcher to audiotape the interview.

Any concerns could be addressed by reminding the participant of the confidentiality clause and that only the researcher will hear the tapes, and how securely they will be stored. The researcher will also support the participant and remind her that she can take a break, refuse to answer any questions or stop at any time should she wish to, without needing to give a reason. Participants will also be encouraged to ask any questions they may have about any aspects of the research. All interviews will be conducted in an empathetic and highly professional manner, showing full respect and consideration for the participants' welfare and needs throughout.

The questions asked will be carefully constructed so to be too difficult for a participant to answer and to reduce any possible distress. In the unlikely event that the participant becomes distressed, they will be supported in using grounding techniques themselves and to reduce any distress before leaving the building.

If the participant has brought a supportive companion along to wait in the waiting area, then the researcher will go and ask them to come and support the participant. The participant would be supported and given options as how to progress. In the rare instance that the situation becomes more serious regarding risk, the police/ ambulance emergency services will be called.

Before the start of the interview, the client will be asked to sign a confidentiality form that clearly states that if anything is disclosed involving harm to self or others, this will need to be reported. If the client was to disclose information of a serious concern to their own or others safety and well-being, the researcher will ask the participant to remain in the room so that further options can be discussed.

Participants from all ethnic and cultural backgrounds will be encouraged to participate in the study to promote the recruitment of a diverse sample of multicultural and ethnic representation. However, it is also acknowledged that only English speaking participants will be recruited in this study. This is due to limited resources and time, and the researcher not speaking welsh or another language.

Risk to researcher

The risk to researcher will involve the risk of lone working when conducting the interviews. In order to reduce the risk and ensure safety of the researcher, the NHS Betsi Cadwaladr lone worker policy will be followed, with recording from a known base, stating the researchers whereabouts and expected time of return.

Data Storage

The interview data will be recorded on an NHS/NCWPP digital audio recorder, which will be safely stored in a secure locked filing cabinet on NHS/NWCPP premises. Data which has been transcribed on a password protected computer will be stored safely on a password protected and encrypted memory stick which will also be safely stored in a secure locked filing cabinet on NHS/ NWCPP premises.

A6-3. Proportionate review of REC application *The initial project filter has identified that your study may be suitable for proportionate review by a REC sub-committee. Please consult the current guidance notes from NRES and indicate whether you wish to apply through the proportionate review service or, taking into account your answer to A6-2, you consider there are ethical issues that require consideration at a full REC meeting.*

○ Yes - proportionate review ◉ No - review by full REC meeting

Further comments (optional):

Note: This question only applies to the REC application.

3. PURPOSE AND DESIGN OF THE RESEARCH

A7. Select the appropriate methodology description for this research. *Please tick all that apply:*

- ☐ Case series/ case note review
- ☐ Case control
- ☐ Cohort observation
- ☐ Controlled trial without randomisation
- ☐ Cross-sectional study
- ☐ Database analysis
- ☐ Epidemiology
- ☐ Feasibility/ pilot study
- ☐ Laboratory study
- ☐ Metanalysis
- ☑ Qualitative research
- ☑ Questionnaire, interview or observation study
- ☐ Randomised controlled trial
- ☐ Other (please specify)

A10. What is the principal research question/objective? *Please put this in language comprehensible to a lay person.*

What strategies and techniques may females with Autism who are higher functioning be using, in order to mask their social skills deficits in the social arena, and when, how and why might they do this?

A11. What are the secondary research questions/objectives if applicable? *Please put this in language comprehensible to a lay person.*

1. What age they first started noticing they were different from their peers?
2. What motivated them to camouflage their social skills deficits?
3. How and from whom have they developed or learned such skills/ techniques?

A12. What is the scientific justification for the research? *Please put this in language comprehensible to a lay person.*

There is current evidence within clinical practice to suggest that females are receiving diagnoses later on in adolescence and adulthood. This has led to further debates as to whether the proposed 4.3:1 sex ratio for Autism is a true reflection of its prevalence in females. Additionally, it highlights the need for clinicians to be aware of the proposed gender differences between males and females on the spectrum and how they may behaviourally present during assessment.

Due to evidence that females with Autism who are higher functioning (HFA) are being undiagnosed, misdiagnosed or diagnosed later on in life due to being 'missed', it begs the question as to why and how this is occurring. Is it due to a 'male bias' in the clinical understanding and assessment of HFA? Or is it conversely (or additionally) due to females

using specific techniques and strategies that allow them to go unnoticed in comparison to their male counterparts? The latter is a research area which is slowly receiving increasing attention.

Superficial Sociability

There is evidence to suggest that one of the reasons why females with HFA may be 'missed' with regards to a diagnosis, is due to their abilities in 'masking' or 'camouflaging' their social skills deficits in the social arena (Atwood, 2007).

Lai et al. (2011) found that adult women with HFA presented with fewer socio-communication impairments in comparison to adult men, and also self-reported more autistic traits than males, suggesting a possible heightened awareness of their difficulties. Therefore, if females are more aware of their difficulties, they may make more efforts than males to try to be accepted by others, to 'fit in' or conversely, to go unnoticed.

Müller, Schuler, & Yates (2008) also found that adults with HFA aged 18-62 years described the experience of having to navigate the social arena as isolating and challenging, which led some participants to observe and model the behaviour of their peers, siblings or colleagues in order to superficially present as 'socially skilled'. However, this was minimally addressed in this paper, and only 5 of the 18 participants were female, therefore the results may not be generalizable to the female HFA population as a whole.

There are findings that suggest that females are better at pretend play and social imitation than males in childhood, which result in their underlying social skills deficits being masked (Attwood, 2007; Cridland et al.,2014; Solomon et al., 2012), until adolescence or early adulthood where changes in relationship complexities and social environments challenge and strain their abilities to continue to camouflage and mask. Due to the possible imitation of social behaviour, parents of HFA daughters have reported finding the diagnostic process challenging, due to clinicians being hesitant in committing to giving a formal diagnosis (Cridland et al., 2014).

Evidence of females potentially masking their social skills deficits in the social arena are also evidenced across the media in radio interviews, autobiographies and self-help books for females with HFA. For example, Temple Grandin (1992) openly describes how she avidly observed human behaviour, and achieved social success through rote learning of how to act in different situations, using certain 'social scripts' she recalled from previous conversations. The author of the popular novel 'Pretending to be normal: Living with Asperger's Syndrome' Liane Willey (1999) also describes how she would camouflage her social confusion by acting out different 'personas' created from famous icons or people she knew, by mimicking their speech, phrases, clothing and body language. She also recalls hiding on the periphery of groups in order to go unnoticed (Willey, 1999).

It has also been proposed that females' HFA traits may also be masked by having special interests in areas that are typically non-male such as fashion, animals, nature, or another particular interest in the realm of social interaction, making these special interests harder to detect in social and communicative contexts (Attwood, 2007). This is in comparison to the male-typical special interests observed in HFA such as automobiles, history, sports, engineering, trains, etc.

Gaps in the literature

The question with regards to how and why females may be masking and camouflaging their socio-communicative deficits in the social arena still remains inadequately addressed in the literature. Some suggest that females with HFA may experience more pressure and expectation to be empathetic, sensitive and develop friendships that rely heavily on reciprocity and communication than their male counterparts (Kopp & Gillberg, 1992), and that a potentially increased awareness of their differences from their neurotypical peers may drive them to consciously or unconsciously mask their difficulties through means of imitation, acting or using certain techniques in order to go unnoticed. For example, some females may try to go unnoticed by avoiding being the centre of attention, by being quietly behaved and being overly apologetic or passive (Attwood, 2007).

However, to date there is minimal research that has attempted to specifically ask women with HFA exactly what it is they do to present as superficially skilled in social situations; what age they first started noticing they were different from their peers; what motivated them to camouflage their social deficits, and how and from whom they developed or learned such skills/ techniques. Such research would not only aid our understanding of HFA and the female HFA phenotype, but also the gender differences in HFA. Greater insight could inform clinicians and the development of assessments used to aid diagnosis. This may reduce the number of females with HFA who go unnoticed or misdiagnosed, and ensure earlier diagnoses for females to aid access to appropriate support.

A13. Please summarise your design and methodology. *It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.*

Participant recruitment

One group of female adults (N = 8) with a diagnosis of Autism who are higher functioning (HFA), will be recruited in order to address the research questions identified above. The consenting participants will be 8 adult women with a current diagnosis of HFA with an IQ of 70 or more, who are English speaking, aged 19-60 years, without any language impairment or intellectual disability.

Recruitment

Participants will be recruited through connections with Research Supervisor Senior Chartered Clinical Psychologist Dr Kristina Cole and Research Collaborator ASD Development Worker David Oliver who will only assist with the recruitment of participants. It is already known that the approximate number of individuals who can be contacted via these key professional sources may be up to 20 individuals, which may allow for the average 40% response rate to research recruitment seen in other studies.

Recruitment will be conducted through the support of the above professionals, who would provide support to contact potential paritipcants (initially by telephone if possible) to see if they would be interested in taking part in the research. Verbal interest in the study would lead to the potential participant being sent an A4 participant information pack in a sealed brown envelope by post, from the principal investigator Aimee Hooper.

This A4 information pack would include a participant information sheet created by the researcher, explaining what the research would involve, why this research is being carried out, and provide information about the procedure of reporting back to all participants with the findings. In this document would also be the location of the interviews, the approximate time length of the interviews, and information regarding audio-taping and the reimbursement of travel costs. Privacy and confidentiality and the limits for this regarding risk/concern would be explained, and storage of digital audio tapes and forms would be explained.

In this pack would also be a consent form and a prepaid envelope, allowing the participant to reply yes or no to consenting to take part in the research, requiring them to provide their address or telephone number for future contact nearer to the research date, explaining that this personal information would be kept confidential and not shared with any other parties. The consent form will have four sections: i) for consent to be an active participant; ii) consent for having understood limits of confidentiality; iii) consent to be contacted nearer the research date to book the interview slot and confirm the location.

Design and Procedures

Participants who consent to participate will be contacted by telephone or by letter inviting them to an interview at a set location at a set time, and will be given an opportunity to change this date and time if not convenient. Those contacted by telephone will be able to change this interview during the telephone call, and those who are contacted by letter will be asked to contact the researcher by telephone at their work base should they need to change their scheduled interview time.

The consenting participants will be invited to a semi-structured interview with the researcher on a set day and time at a set location, lasting for approximately 60-80 minutes. Participants will be able to bring a supportive companion with them if they so wish, who would be asked to sit in the waiting area whilst the interview took place. Audio-taping consent and confidentiality forms will be given to the participant before commencing the interview, in order to allow the researcher to progress to audio-taping the interview. The participants will be asked semi-structured questions with prompts if required pertaining to the above research questions and the interview will be audio-taped.

The interview questions will begin in a general and broad nature, allowing for the participants to lead the conversation. Further structured questions will also be asked with prepared set prompts should prompting be needed. Participants will be adequately informed that they can ask questions, have a break, stop or refuse to answer any questions should they feel the need to. Refreshments will be made available in the interview room, and they will be able to stop and speak to their supportive companion should they so wish for extra support.

The research will take place at Bangor University NWCPP department or at Roslin Community Mental Health Team base in Craig-Y-Don, depending on the participants' ability to travel and the distance of their home or work address from Bangor University. Participants will be refunded their travel expenses for the interview on the day up to a maximum cost of £18.00.

Measures

Some of the demographic data to be collected for each group will be as follows:
- Age
- Marital Status

• Employment Status
• Age of formal diagnosis of Autism (Higher Functioning)

Data Management and Analysis

The interview data will be recorded on an NHS/NCWPP digital audio recorder, which will be safely stored in a secure locked filing cabinet on NHS/NWCPP premises. Data which has been transcribed on a password protected computer will be stored safely on an NHS/NWCPP password protected and encrypted memory stick which will also be stored in a secure locked filing cabinet on NHS/NWCPP premises.

Analysis

Due to the qualitative nature of the data the transcribed interviews will be analysed using the qualitative method of Applied Thematic Analysis (ATA; Guest, MacQueen & Namey, 2012). ATA is highly credible and would allow the trainee to identify and examine themes from the interview data in a systematic, efficient and ethical way that would facilitate transparency of the methods and procedures used (Guest et al., 2012). ATA would also support the demonstration of methodological and analytic rigour for a VIVA.

The aforementioned research question is suitable for this form of analysis, as well as the proposed sampling and data collection methods. A sample size of 8 participants is an acceptable sample size for ATA. Semi-structured interviews work well with ATA as they are objective collections of the participants' lived story – "words will speak for themselves…" (Starks & Trinidad, 2007). The use of probing questions and prompts will therefore be appropriate for ATA, in order to encourage the participants to elaborate when necessary. Relevant literature, manuals and online resources will be accessed.

All interviews will be carried out first, and then each interview will be analysed and coded in order of the date in which they were conducted. With regards to the presentation of the findings, they may be presented diagrammatically.

The audience for this piece of research is appropriate and representative of the audiences usually aimed at by ATA – clinicians, researchers and other professionals.

A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

- ☐ Design of the research
- ☐ Management of the research
- ☐ Undertaking the research
- ☐ Analysis of results
- ☐ Dissemination of findings
- ☑ None of the above

Give details of involvement, or if none please justify the absence of involvement.

4. RISKS AND ETHICAL ISSUES

RESEARCH PARTICIPANTS

A15. What is the sample group or cohort to be studied in this research?

Select all that apply:

- ☐ Blood
- ☐ Cancer
- ☐ Cardiovascular
- ☐ Congenital Disorders
- ☐ Dementias and Neurodegenerative Diseases

- ☐ Diabetes
- ☐ Ear
- ☐ Eye
- ☐ Generic Health Relevance
- ☐ Infection
- ☐ Inflammatory and Immune System
- ☐ Injuries and Accidents
- ☐ Mental Health
- ☐ Metabolic and Endocrine
- ☐ Musculoskeletal
- ☐ Neurological
- ☐ Oral and Gastrointestinal
- ☐ Paediatrics
- ☐ Renal and Urogenital
- ☐ Reproductive Health and Childbirth
- ☐ Respiratory
- ☐ Skin
- ☐ Stroke

Gender:	Female participants only
Lower age limit: 19	Years
Upper age limit: 60	Years

A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).

Adult women with a current diagnosis of Autism who are higher functioning; with an IQ of 70 or more; who are English speaking; aged 19-60 years; without any language impairment or intellectual disability.

A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).

Males; Adult women without a diagnosis of Autism; Adult women with a diagnosis of Autism who are not high functioning; with an IQ of less than 70; who do not speak English; who are aged under 19 years or aged over 60 years; who have a language impairment or intellectual disability.

RESEARCH PROCEDURES, RISKS AND BENEFITS

A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. *These include seeking consent, interviews, non-clinical observations and use of questionnaires.*

Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?
3. Average time taken per intervention/procedure (minutes, hours or days)
4. Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	1	2	3	4
Approached regarding the research	1	0	15 mins	Research supervisor Dr Kristina Cole from Roslin CMHT or Research Collaborator David Oliver, ASD worker for Anglesey and Conwy County

				Councils - via appointments or telephone
Receive information sheets in an A4 pack	1	0	20 mins	To be sent by researcher Aimee Hooper to address of the potential participants for them to read and decide if they would like to take part.
Give request and consent to participate	1	0	15 mins	Participant to reply using pre-paid stamped envelope only if agreeing to participate with written signed consent to taking part in the research.
Give consent to being audiotaped during interview	1	0	10 mins	Researcher Aimee Hooper to request and gain written signed consent from participant to having interview audio recorded before conducting interview, at interview location.
Explaining confidentiality and the limits of this	1	1	10 mins	Researcher Aimee Hooper to explain confidentiality and the limits of this before proceeding with interview, at interview location.
Research interview	1	0	60-80 mins	Researcher Aimee Hooper to conduct interview with participant at chosen interview location - either Roslin CMHT; local GP practice or; Bangor University.
Dissemination of research results	1	0	15	Report of the results will be sent to participant by researcher Aimee Hooper to participants address, unless they specifically ask to not be contacted after the interview. Results would be sent in stamped envelope addressed only to the participant, marked as 'private & confidential'.

A21. How long do you expect each participant to be in the study in total?

From being sent the information sheet to being sent results of the research findings, participants will be involved in the study on some level for a maximum of 19 months. However, participants will only actually be actively involved in the research process for approximately 3 hours in total.

A22. What are the potential risks and burdens for research participants and how will you minimise them?

For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.

Risk to participants

The likely problematic aspects to arise may be in participants feeling uncomfortable in being audio-taped during the interview. This will require consent and confidentiality forms to be given to the participant and signed by participant and researcher before commencing the interview, in order to allow the researcher to progress and audiotape the interview. Any concerns could be addressed by reminding the participant of the confidentiality clause and that only the researcher will hear the tapes, and how securely they will be stored, and so on. The researcher will also support the participant and remind them that they can take a break, refuse to answer any questions or stop at any time should they wish to, without needing to give a reason. They will also be encouraged to ask any questions they may have about any aspects of the research at any time and stop to speak to a supportive companion should they have come to the interview with the participant for support.

To reduce any possible distress during interview, the questions asked will be carefully constructed so to not provoke distress or be too difficult for a participant to answer. All interviews will be conducted in an empathetic and highly professional manner, showing full respect and consideration for the participants' welfare and needs throughout and the participant will be reminded of their free will to stop, leave, or take a break and speak to a supportive companion seated in the waiting area, should they so wish.

Participants from all ethnic and cultural backgrounds will be encouraged to participate in the study to promote the recruitment of a diverse sample of multi-cultural and ethnic representation. However, it is also acknowledged that only English speaking participants will be recruited in this study. This is due to limited resources and time, and the researcher not speaking welsh or another language. This will again be something to be reflected on in the paper's discussion, particularly with regards to conducting the research in a Welsh speaking country.

The participant will be supported in grounding themselves and reducing their distress before leaving the building, discussing possible options with Aimee Hooper. In the rare event that the situation becomes increasingly serious with regards to risk, the police/ ambulance emergency services will be called.

Data Storage

The interview data will be recorded on an NHS/NCWPP digital audio recorder, which will be safely stored in a secure locked filing cabinet on NHS/NWCPP premises. Data which has been transcribed on a password protected computer will be stored safely on a password protected and encrypted memory stick which will also be stored in a secure locked filing cabinet on NHS/NWCPP premises.

A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?

(●) Yes ( ) No

If Yes, please give details of procedures in place to deal with these issues:

To reduce any possible distress during interview, the questions asked will be carefully constructed so to not provoke distress or be too difficult for a participant to answer. All interviews will be conducted in an empathetic and highly professional manner, showing full respect and consideration for the participants' welfare and needs throughout and the participant will be reminded of their free will to stop, leave or take a break should they so wish, or speak to a supportive companion if they came accompanied.
The participant will be supported in grounding themselves and work on reducing their distress before they leave the building. In the rare event that the situation becomes more serious with regards to risk, the police/ ambulance emergency services will be called.
If the client was to disclose information of a serious concern to their own or others safety and well-being, they would be able to discuss possible the next possible options with researcher Aimee Hooper.

A24. What is the potential for benefit to research participants?

We cannot promise the study will help participants, but the information we get from the study may help to increase the understanding, diagnosis and treatment of women with Autism. The participants may also gain a positive and validating experience from being listened to and given an opportunity to have their voice heard, with the knowledge that it is contributing to psychological research.

A26. What are the potential risks for the researchers themselves? *(if any)*

The risk to researcher will involve the risk of lone working when conducting the interviews. In order to reduce the risk and ensure safety of the researcher, the BCUHB lone working policy will be followed, with recording from a known base, and stating the researcher's whereabouts and expected time of return.

RECRUITMENT AND INFORMED CONSENT

In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.

A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used?*For example, identification may involve a disease register, computerised search of social care or GP records, or review of medical records. Indicate whether this will be done by the direct care team or by researchers acting under arrangements with the responsible care organisation(s).*

Dr Kristina Cole and Mr David Oliver (ASD Development Worker) have been informed about the study and have agreed to identify potential participants, using the provided inclusion and exclusion criteria that will at the required time be given to them by the researcher Aimee Hooper. They will discuss the research with the potential participant, and if the individual wishes to know more about the research, the researcher will be notified of the potential participants who will then be sent the information sheet and consent forms in a pack through the post in a sealed brown envelope marked as private and confidential, and addressed only to that person.

A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?

( ) Yes (●) No

Please give details below:

A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?

○ Yes ◉ No

A29. How and by whom will potential participants first be approached?

Potential participants will first be approached by either Dr. Kristina Cole or Mr David Oliver, who will briefly tell them about the research to see if they would like to know more about it or consider taking part.
Those who express an interest will be sent an A4 information pack in the post by Aimee Hooper.

A30-1. Will you obtain informed consent from or on behalf of research participants?

◉ Yes ○ No

If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.

If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.

All participants willing to take part in the study will be asked to complete a consent form, which will be provided in the initial information pack, requiring the participant to answer some essential questions and provide a written signature to declare they are agreeing to take part.
Participants will also be asked for their consent for direct quotations to be used from the recording of the interviews if selected.
Participants will also be asked for their preferred address or telephone contact number (i.e. mode of contact) for the researcher to contact them on in the future, so to arrange the interview date and time.

Also, in the information pack participants will be made aware that as a part of the study, the interviews will be audio recorded in order to gather the qualitative data that the research question requires. On the day of the interview the participant will be asked to complete an audio taping consent form, reminding them that the interview will be audio recorded and asking the participant for written consent for their interview to be recorded, before being able to conduct the interview.

If you are not obtaining consent, please explain why not.

Please enclose a copy of the information sheet(s) and consent form(s).

A30-2. Will you record informed consent (or advice from consultees) in writing?

◉ Yes ○ No

A31. How long will you allow potential participants to decide whether or not to take part?

Two weeks

A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs? *(e.g. translation, use of interpreters)*

As part of the inclusion criteria, only participants who speak English and can read written English who have no speech and language impairment or learning disability will be included in the study. The reasons for this are justifiable, as the research is looking specifically at women with Autism who are higher functioning, and as a part of this criteria would not be classed as high functioning if they had a speech and language impairment or learning disability. Also, if the client was to have a speech and language impairment, it is a possibility that they might find the interview difficult or distressing.

Also, the researcher does not speak Welsh, and therefore would not be able to conduct the interviews through the medium of welsh, and a translator would not be available during interviews as it would not be covered by the limited budget and time provided to conduct the research.

However, all information sheets and consent forms will not only be provided in the medium of the English language but will also be translated into the medium of Welsh and provided to the participants.

A33-2. What arrangements will you make to comply with the principles of the Welsh Language Act in the provision of information to participants in Wales?

All information sheets and consent forms will not only be provided in English but will also be translated into the medium of Welsh and provided to the participants. However, the interviews will not be conducted in the welsh language and and a translator would not be available as it would not be covered by the limited budget and time available to conduct the research.

A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? *Tick one option only.*

- ○ The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.
- ◉ The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.
- ○ The participant would continue to be included in the study.
- ○ Not applicable – informed consent will not be sought from any participants in this research.
- ○ Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

Further details:

If the data has already been collected, then as a sign of respect to the participant and the time they gave to the study, their data will still be used for analysis.
Upon completing the study, it will be recorded that the participant lost capacity to provide informed consent and this record will be kept, but the data will not be made available to the research team after this stage.

If you plan to retain and make further use of identifiable data/tissue following loss of capacity, you should inform participants about this when seeking their consent initially.

CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

Storage and use of personal data during the study

A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)?*(Tick as appropriate)*

- ☐ Access to medical records by those outside the direct healthcare team
- ☐ Access to social care records by those outside the direct social care team
- ☐ Electronic transfer by magnetic or optical media, email or computer networks
- ☐ Sharing of personal data with other organisations
- ☐ Export of personal data outside the EEA
- ☑ Use of personal addresses, postcodes, faxes, emails or telephone numbers
- ☑ Publication of direct quotations from respondents
- ☐ Publication of data that might allow identification of individuals

- [x] Use of audio/visual recording devices
- [ ] Storage of personal data on any of the following:
  - [ ] Manual files (includes paper or film)
  - [ ] NHS computers
  - [ ] Social Care Service computers
  - [ ] Home or other personal computers
  - [ ] University computers
  - [ ] Private company computers
  - [ ] Laptop computers

Further details:
Information sheets and consent forms in a pack will be sent to the interested potential participants.
Those who agree to participate will be asked for their preferred mode of contact (i.e. address or telephone number) for the researcher to contact them on to arrange the interview time, date and location.
This means addresses and/or telephone numbers of participants will only be provided to the researcher by those wishing to participate in the study, and completed forms will be kept in a secure locked cabinet on BCUHB/ NWCPP premises.

Direct quotations may be published in the written research report, which will be clearly explained in the information sheet and participants will be asked for their consent on this on the consent form. Direct quotations will not be used for participants who do not give consent.

All interviews will need to be digitally recorded. This recording will be conducted using an NWCPP digital audio recorder which will be kept on Bangor University (NWCPP)/ BCUHB (Roslin CMHT) premises in a locked cabinet, accessed by only the researcher. The recorded interviews will be transferred onto an encrypted BCUHB/NWCPP USB stick for analysis and used on a password protected laptop, but recordings and files containing transcriptions will only be stored and saved on the encrypted USB stick, not on any other device.

A37. Please describe the physical security arrangements for storage of personal data during the study?

The audio digital recorder, USB stick and completed consent forms will be stored in a secure locked filing cabinet on BCUHB (Roslin CMHT)/ NWCPP (Bangor University) premises which only the researcher Aimee Hooper will have access to. Once the interviews have been completed, the consent forms will be placed in the participants clinical file by Aimee Hooper. The encrypted USB stick will have a password known only by the researcher. Audio recordings and transcriptions will only be saved on the USB stick.

A38. How will you ensure the confidentiality of personal data?*Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.*

All personal data about participants (i.e. names, places, and specific information)
will be anonymous on transcripts to prevent identification - each participant will be given a participant number. The researcher will follow the policy and guidance of the Data Protection Act (1998) and the codes of practice for confidentiality, information governance and information security. The audio digital recorder, consent forms, and encrypted USB stick will be stored in a secure locked filing cabinet on BCUHB/ NWCPP premises, accessible by only the researcher and the encrypted USB stick will have a password known only by the researcher.

A40. Who will have access to participants' personal data during the study? *Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.*

The researcher Aimee Hooper will require the address/ telephone number of all consenting participants in order to make contact to arrange the interview location, date and time. Consent forms with the above information on will be filed in a secure locked cabinet on BCUHB/ NWCPP premises. Once the interviews have been completed the consent forms will be placed in the participants clinical file by Aimee Hooper.

Storage and use of data after the end of the study

A41. Where will the data generated by the study be analysed and by whom?

The research interviews will be transcribed and analysed by researcher Aimee Hooper, who will be conducting the analysis on BCUHB/ NWCPP premises.

A42. Who will have control of and act as the custodian for the data generated by the study?

Title	Forename/Initials	Surname
Mrs	Aimee	Hooper

Post	Trainee Clinical Psychologist
Qualifications	BSc Applied Psychology - First Class Honours.
Work Address	North Wales Clinical Psychology Programme (NWCPP), Department of Psychology, 43 College Road, Bangor, Gwynedd
Post Code	LL57 2DG
Work Email	psp2ce@bangor.ac.uk
Work Telephone	01248382205
Fax	

A43. How long will personal data be stored or accessed after the study has ended?

- (●) Less than 3 months
- ( ) 3 – 6 months
- ( ) 6 – 12 months
- ( ) 12 months – 3 years
- ( ) Over 3 years

A44. For how long will you store research data generated by the study?

Years: 3
Months: 0

A45. Please give details of the long term arrangements for storage of research data after the study has ended. *Say where data will be stored, who will have access and the arrangements to ensure security.*

Research data (i.e. anonymous interview recordings) on the encrypted USB stick will be handed over to NWCPP Bangor University as a requirement of the researcher's clinical training, for it to be stored in a secure locked cabinet. After 3 years the USB stick will be wiped and any data on the stick will therefore be destroyed of safely and securely.

INCENTIVES AND PAYMENTS

A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?

(●) Yes ( ) No

If Yes, please give details. For monetary payments, indicate how much and on what basis this has been determined.
Participants will have their expenses for travelling to the interview reimbursed up to a total of £18.00 on the day of the interview, which will be funded by NWCPP Bangor University. The travel expenses will be reimbursed to the participant upon arrival to the interview before the interview takes place to reduce any anxieties or stress the participant may have

about this, so not to impact on the interview process.

A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?

○ Yes ◉ No

A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?

○ Yes ◉ No

NOTIFICATION OF OTHER PROFESSIONALS

A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?

◉ Yes ○ No

If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.

A49-2. Will you seek permission from the research participants to inform their GP or other health/ care professional?

◉ Yes ○ No

It should be made clear in the participant's information sheet if the GP/health professional will be informed.

PUBLICATION AND DISSEMINATION

A50-1. Will the research be registered on a public database?

○ Yes ◉ No

Please give details, or justify if not registering the research.
This research will not be registered on a public database, as it will not be publicly funded. However, a paper copy of the Doctoral Thesis will be kept on file and securely stored in the library at Bangor University.

Registration of research studies is encouraged wherever possible.
You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you are aware of a suitable register or other method of publication, please give details. If not, you may indicate that no suitable register exists. Please ensure that you have entered registry reference number(s) in question A5-1.

A51. How do you intend to report and disseminate the results of the study? *Tick as appropriate:*

- ☑ Peer reviewed scientific journals
- ☐ Internal report
- ☑ Conference presentation
- ☐ Publication on website
- ☐ Other publication
- ☐ Submission to regulatory authorities
- ☐ Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators

☐ No plans to report or disseminate the results
☐ Other (please specify)

A52. If you will be using identifiable personal data, how will you ensure that anonymity will be maintained when publishing the results?

All interviews will be anonymised and participants will be given a participant number so not to use any personal identifiers, and any direct quotes used in the scientific report and in publication will also be anonymous with no personal identifiers left in, and only used with the participants consent to do so.

A53. Will you inform participants of the results?

◉ Yes ○ No

Please give details of how you will inform participants or justify if not doing so.
Participants will be asked at the end of the interview if they would like to be contacted again by letter with information on the results of the study, which would be in a stamped brown envelope addressed only to the participant, marked as private and confidential.
Participants who do not wish to be contacted again after the interviews with the results will not be contacted, in respect of their request.

5. Scientific and Statistical Review

A54-1. How has the scientific quality of the research been assessed? *Tick as appropriate:*

☐ Independent external review
☐ Review within a company
☐ Review within a multi–centre research group
☑ Review within the Chief Investigator's institution or host organisation
☑ Review within the research team
☑ Review by educational supervisor
☐ Other

Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:
A detailed research proposal has been submitted, checked and approved by the research team at NWCPP, Bangor University. The Bangor University Psychology Ethics board has also approved the research project at the time of submitting this form.

For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.

For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.

A59. What is the sample size for the research? *How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.*

Total UK sample size:	8
Total international sample size (including UK):	8
Total in European Economic Area:	0

Further details:
Due to the qualitative methodology and data analysis involved in this study, a sample size of 8 participants was deemed most appropriate to fit in with the available time scale and resources available to the researcher.

A60. How was the sample size decided upon? *If a formal sample size calculation was used, indicate how this was done,*

giving sufficient information to justify and reproduce the calculation.

A minimum of 4 and maximum of 10 participants is generally recommended when analyzing qualitative interview data on a limited time frame, mainly due to the time consuming nature of coding and analyzing the interviews - it takes on average ten hours to code and analyse one hour of an interview. Therefore 8 was deemed a reasonable sample size that would provide the researcher with enough time to conduct the analyses without having a sample size that is too small.

A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.

Due to the qualitative nature of the data the transcribed interviews will be analysed using the qualitative method of Applied Thematic Analysis (ATA; Guest, MacQueen & Namey, 2012). ATA is highly credible and would allow the trainee to identify and examine themes from the interview data in a systematic, efficient and ethical way that would facilitate transparency of the methods and procedures used (Guest et al., 2012). ATA would also support the demonstration of methodological and analytic rigour for a VIVA.
The aforementioned research question is suitable for this form of analysis, as well as the proposed sampling and data collection methods. A sample size of 8 participants is an acceptable sample size for ATA. Semi-structured interviews work well with ATA as they are objective collections of the participants' lived story – "words will speak for themselves…" (Starks & Trinidad, 2007). The use of probing questions and prompts will therefore be appropriate for ATA, in order to encourage the participants to elaborate when necessary. Relevant literature, manuals and online resources will be accessed.
All interviews will be carried out first, and then each interview will be analysed and coded in order of the date in which they were conducted. With regards to the presentation of the findings, they may be presented diagrammatically.
The audience for this piece of research is appropriate and representative of the audiences usually aimed at by ATA – clinicians, researchers and other professionals.
The research team at NWCPP Bangor University will be available and contactable should further guidance on the qualitative analysis be required/ advised.

6. MANAGEMENT OF THE RESEARCH

A63. Other key investigators/collaborators. *Please include all grant co–applicants, protocol co–authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.*

	Title	Forename/Initials	Surname
	Dr	Kristina	Cole
Post	Chartered Clinical Psychologist		
Qualifications	DClinPsy (Doctorate of Clinical Psychology)		
Employer	Betsi Cadwaladr University Health Board		
Work Address	Roslin CMHT, Nant Y Gamar Road,		
	Craig Y Don, Llandudno, Conwy		
Post Code	LL30 1YE		
Telephone	01492 860926		
Fax			
Mobile			
Work Email	kristina.cole@wales.nhs.uk		

	Title	Forename/Initials	Surname
	Mr	David	Oliver
Post	ASD Development Worker		
Qualifications			
Employer	Gwynedd Council		
Work Address	Gwynedd & Ynys Mon, Social Services,		

	Gwynedd Council, Arfon Area Office, Penrallt, Caernarfon, Gwynedd.
Post Code	LL55 1BN
Telephone	01286682751
Fax	
Mobile	07909034319
Work Email	DavidOliver@gwynedd.gov.uk

A64. Details of research sponsor(s)

A64-1. Sponsor

Lead Sponsor

Status: ○ NHS or HSC care organisation Commercial status: Non-Commercial
◉ Academic
○ Pharmaceutical industry
○ Medical device industry
○ Other

If Other, please specify:

Contact person

Name of organisation	Bangor University School of Psychology
Given name	Hefin
Family name	Francis
Address	School of Psychology
Town/city	Bangor
Post code	LL7 2AS
Country	UNITED KINGDOM
Telephone	01248388339
Fax	
E-mail	H.Francis@bangor.ac.uk

Is the sponsor based outside the UK?
○ Yes ◉ No

Under the Research Governance Framework for Health and Social Care, a sponsor outside the UK must appoint a legal representative established in the UK. Please consult the guidance notes.

A65. Has external funding for the research been secured?

☐ Funding secured from one or more funders
☐ External funding application to one or more funders in progress
☑ No application for external funding will be made

What type of research project is this?

- (●) Standalone project
- ( ) Project that is part of a programme grant
- ( ) Project that is part of a Centre grant
- ( ) Project that is part of a fellowship/ personal award/ research training award
- ( ) Other

Other – please state:

A66. Has responsibility for any specific research activities or procedures been delegated to a subcontractor (other than a co-sponsor listed in A64-1) ? *Please give details of subcontractors if applicable.*

( ) Yes (●) No

A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?

( ) Yes (●) No

Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.

A68-1. Give details of the lead NHS R&D contact for this research:

	Title	Forename/Initials	Surname
	Mr	Sion	Lewis
Organisation	Betsi Cadwaladr University Health Board		
Address	Research & Development,		
	Ysbyty Gwynedd,		
	Bangor, Gwynedd.		
Post Code	LL57 2PW		
Work Email	Sion.Lewis@wales.nhs.uk		
Telephone	01248384877		
Fax			
Mobile			

Details can be obtained from the NHS R&D Forum website: http://www.rdforum.nhs.uk

A69-1. How long do you expect the study to last in the UK?

Planned start date: 01/06/2015
Planned end date: 31/07/2016
Total duration:
Years: 1 Months: 1 Days: 31

A71-1. Is this study?

- ( ) Single centre
- (●) Multicentre

A71-2. Where will the research take place? *(Tick as appropriate)*

- ☐ England
- ☐ Scotland
- ☑ Wales
- ☐ Northern Ireland
- ☐ Other countries in European Economic Area

Total UK sites in study 2

Does this trial involve countries outside the EU?

○ Yes ◉ No

A72. Which organisations in the UK will host the research?*Please indicate the type of organisation by ticking the box and give approximate numbers if known:*

☐ NHS organisations in England	
☑ NHS organisations in Wales	1
☐ NHS organisations in Scotland	
☐ HSC organisations in Northern Ireland	
☐ GP practices in England	
☐ GP practices in Wales	
☐ GP practices in Scotland	
☐ GP practices in Northern Ireland	
☐ Joint health and social care agencies (eg community mental health teams)	
☐ Local authorities	
☐ Phase 1 trial units	
☐ Prison establishments	
☐ Probation areas	
☐ Independent (private or voluntary sector) organisations	
☑ Educational establishments	1
☐ Independent research units	
☐ Other (give details)	
Total UK sites in study:	2

A73-1. Will potential participants be identified through any organisations other than the research sites listed above?

○ Yes ◉ No

A74. What arrangements are in place for monitoring and auditing the conduct of the research?

The research will be monitored and audited by both the research supervisor Dr Kristina Cole but also the North Wales Clinical Psychology Programme (NWCPP) at Bangor University, which as part of the researcher's DClinPsy training requirements will involve the research team and the researcher's training coordinator liaising with the researcher and the research supervisor on a regular basis to assess the conduct of the researcher. The researcher will also be required to write and submit detailed research progress reports to the NWCPP research team to demonstrate their progress and their professional conduct.

A76. Insurance/ indemnity to meet potential legal liabilities

***Note:* in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland**

A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research? *Please tick box(es) as applicable.*

Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.

☐ NHS indemnity scheme will apply (NHS sponsors only)

☑ Other insurance or indemnity arrangements will apply (give details below)

Bangor University will meet the potential legal liability of the sponsor for harm to participants arising from the management of the research.
Please see attached sponsorship let ter.

Please enclose a copy of relevant documents.

A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research? *Please tick box(es) as applicable.*

Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.

☐ NHS indemnity scheme will apply (protocol authors with NHS contracts only)

☑ Other insurance or indemnity arrangements will apply (give details below)

Bangor University will meet the potential legal liability of the sponsor for harm to participants arising from the management of the research. Please see attached sponsorship letter.

Please enclose a copy of relevant documents.

A76-3. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the conduct of the research?

Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.

☑ NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)

☐ Research includes non-NHS sites (give details of insurance/ indemnity arrangements for these sites below)

NHS Indemnity scheme applies as participants will be NHS patients .

Please enclose a copy of relevant documents.

A78. Could the research lead to the development of a new product/process or the generation of intellectual property?

○ Yes ◉ No ○ Not sure

Full Set of Project Data IRAS Version 3.5

PART C: Overview of research sites

Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites. *For NHS sites, the host organisation is the Trust or Health Board. Where the research site is a primary care site, e.g. GP practice, please insert the host organisation (PCT or Health Board) in the Institution row and insert the research site (e.g. GP practice) in the Department row.*

Research site		Investigator/ Collaborator/ Contact	
Institution name	Betsi Cadwaladr University Health Board	Title	Dr
Department name	Roslin CMHT	First name/ Initials	Kristina
Street address	Nant Y Gamar Road, Craig Y Don	Surname	Cole
Town/city	Llandudno		
Post Code	LL30 1YE		
Institution name	Bangor University	Title	Dr
Department name	NWCPP, Department of Psychology	First name/ Initials	Robert
Street address	43 College Road	Surname	Jones
Town/city	Bangor		
Post Code	LL57 2DG		

PART D: Declarations

D1. Declaration by Chief Investigator

1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.

2. I undertake to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research.

3. If the research is approved I undertake to adhere to the study protocol, the terms of the full application as approved and any conditions set out by review bodies in giving approval.

4. I undertake to notify review bodies of substantial amendments to the protocol or the terms of the approved application, and to seek a favourable opinion from the main REC before implementing the amendment.

5. I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.

6. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer. I understand that I am not permitted to disclose identifiable data to third parties unless the disclosure has the consent of the data subject or, in the case of patient data in England and Wales, the disclosure is covered by the terms of an approval under Section 251 of the NHS Act 2006.

7. I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.

8. I understand that any personal data in this application will be held by review bodies and their operational managers and that this will be managed according to the principles established in the Data Protection Act 1998.

9. I understand that the information contained in this application, any supporting documentation and all correspondence with review bodies or their operational managers relating to the application:

    - Will be held by the REC (where applicable) until at least 3 years after the end of the study; and by NHS R&D offices (where the research requires NHS management permission) in accordance with the NHS Code of Practice on Records Management.
    - May be disclosed to the operational managers of review bodies, or the appointing authority for the REC (where applicable), in order to check that the application has been processed correctly or to investigate any complaint.
    - May be seen by auditors appointed to undertake accreditation of RECs (where applicable).
    - Will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.
    - May be sent by email to REC members.

10. I understand that information relating to this research, including the contact details on this application, may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.

11. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named below. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

Contact point for publication*(Not applicable for R&D Forms)*

NRES would like to include a contact point with the published summary of the study for those wishing to seek further information. We would be grateful if you would indicate one of the contact points below.

(●) Chief Investigator

( ) Sponsor

- ○ Study co-ordinator
- ○ Student
- ○ Other – please give details
- ○ None

Access to application for training purposes *(Not applicable for R&D Forms)*

Optional – please tick as appropriate:

☑ I would be content for members of other RECs to have access to the information in the application in confidence for training purposes. All personal identifiers and references to sponsors, funders and research units would be removed.

Signature: .....

Print Name:

Date: *(dd/mm/yyyy)*

D2. Declaration by the sponsor's representative

If there is more than one sponsor, this declaration should be signed on behalf of the co–sponsors by a representative of the lead sponsor named at A64-1.

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.
2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.
3. Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.
4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.
5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.
6. The duties of sponsors set out in the Research Governance Framework for Health and Social Care will be undertaken in relation to this research.
7. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.
8. Specifically, for submissions to the Research Ethics Committees (RECs) I declare that any and all clinical trials approved by the HRA since 30th September 2013 (as defined on IRAS categories as clinical trials of medicines, devices, combination of medicines and devices or other clinical trials) have been registered on a publically accessible register in compliance with the HRA registration requirements for the UK, or that any deferral granted by the HRA still applies.

Signature: .....

Print Name:

Post:

Organisation:

Date: *(dd/mm/yyyy)*

D3. Declaration for student projects by academic supervisor(s)

1. I have read and approved both the research proposal and this application. I am satisfied that the scientific content of the research is satisfactory for an educational qualification at this level.

2. I undertake to fulfil the responsibilities of the supervisor for this study as set out in the Research Governance Framework for Health and Social Care.

3. I take responsibility for ensuring that this study is conducted in accordance with the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research, in conjunction with clinical supervisors as appropriate.

4. I take responsibility for ensuring that the applicant is up to date and complies with the requirements of the law and relevant guidelines relating to security and confidentiality of patient and other personal data, in conjunction with clinical supervisors as appropriate.

Academic supervisor 1

Signature: .....

Print Name:

Post:

Organisation:

Date: *(dd/mm/yyyy)*

Appendix D: North Wales Research Ethics Committee: Provisional Opinion Subject to Amendments

Pwyllgor Moeseg Ymchwil Cymru 5
Wales Research Ethics Committee 5
Bangor

Clinical Academic Office
Ysbyty Gwynedd Hospital
Betsi Cadwaladr University Health Board
Bangor, Gwynedd
LL57 2PW

Telephone/ Facsimile: 01248 - 384.877
Email: Rossela.Roberts@wales.nhs.uk
Website : www.nres.nhs.uk

Mrs Aimee Jane Hooper
Trainee Clinical Psychologist
NWCPP, School of Psychology,
Brigantia Building, Bangor University,
Bangor, Gwynedd
LL57 2DG psp2ce@bangor.ac.uk

17 April 2015

Dear Mrs Hooper,

Study title:	**A qualitative study looking at the strategies that adult higher functioning women on the autistic spectrum report in order to compensate for and 'mask' social skills deficits.**
REC reference:	**15/WA/0142**
IRAS project ID:	**169142**

The Research Ethics Committee reviewed the above application at the meeting held on 16 April 2015. The Committee wishes to thank you and Dr Cole for attending to discuss the application.

Provisional opinion

The Committee would be content to give a favourable ethical opinion of the research, subject to receiving a complete response to the request for further information set out below.

Authority to consider your response and to confirm the Committee's final opinion has been delegated to the Chair.

Further information or clarification required

Protocol

1. The "Defining autism" section should include a working definition of High Functioning Autism for the purpose of the study.
2. In the 'research question' section, the statement that the study "will improve diagnostic assessment tools and reduce the risk of under or misdiagnosis" should be clarified by providing clear outcome measures or removed.
3. The "participant recruitment" section should clarify that all clinical assessments (IQ, learning disability, etc) and would have been carried out part of the diagnostic process and not part of the research.
4. The procedure to deal with incidental disclosures and the statutory requirement to break confidentiality should be clarified.

Participant Information Sheet

1. The Committee requested that the Information Sheet is proof-read and typographical and grammatical errors are amended.
2. The paragraph "Will my taking part be kept confidential?" should clarify the procedure to deal with incidental disclosures and the statutory duty to breach confidentiality.
3. In paragraph "What will happen next" remove the first sentence "if you do not want to take part[…]" and explain what will happen after they return the slip (the research team will contact them).
4. If the intention is to inform the GP this should be clearly discussed in the Information sheet.
5. The Welsh language version of the PIS needs to clarify that the interviews will be conducted in English.
6. Committee suggested that the lay version of the project title and the aims of the project as described in the information for participants may be rephrased to avoid attaching labels and convening negative values (skills deficit). It could be re-phrased to read, for example "interactions among females with high functioning autism" – this is a suggestion only and not a condition of ethical approval.

Supporting information

1. The Committee requested that the Interview Schedule is revisited and the interview prompts are re-phrased to avoid leading questions.

REC application form (IRAS)

1. The Committee requested that the study summary as it appears in section A6-1 of the REC application form is re-written to use lay language, to reflect the aims of the study in concordance with the outcome measures and avoid unnecessary details (e.g. where the interviews will take place). The REC application form should be duly authorised and re-submitted.

If you would find it helpful to discuss any of the matters raised above or seek further clarification from a member of the Committee, you are welcome to contact Dr Rossela Roberts, RES manager, at the address in the letterhead.

When submitting a response to the Committee, the requested information should be electronically submitted from IRAS. A step-by-step guide on submitting your response to the REC provisional opinion is available on the HRA website using the following link: http://www.hra.nhs.uk/nhs-research-ethics-committee-rec-submitting-response-provisional-opinion/

Please submit revised documentation where appropriate underlining or otherwise highlighting the changes which have been made and giving revised version numbers and dates.

The Committee will confirm the final ethical opinion within a maximum of 60 days from the date of initial receipt of the application, excluding the time taken by you to respond fully to the above points. A response should be submitted by no later than 17 May 2015.

Summary of the discussion at the meeting

Ethical issues raised by the Committee in private discussion, together with responses given by you and Dr Cole when invited to join the meeting

The Chairman welcomed the you and introduced the Committee members.

The following issues were discussed:

Social or scientific value; scientific design and conduct of the study
The Committee considered whether the objectives, design, methodology, and the conduct of the study are appropriately described in the protocol.
A query was raised in relation to the defined target sample; the protocol states that females with high functioning autism and an IQ of 70 plus will be approached; a working definition of high functioning autism (for the purpose of the study) is required.
Similarly a clarification of how and when the IQ is being measured needs to be included and a strategy to account for differences in performance between and IQ of 70 and 100.
You clarified that diagnostic of high functioning autism would have been confirmed by the service and IQ is not formally measured during the study. The inclusion and exclusion criteria clarifies that females with learning disabilities will not be approached and the interview strategies as detailed in the prompt sheet will mitigate for individual differences.
The Committee requested that this is detailed in the protocol.
The Committee queried whether it is likely to come across ethnic differences and whether compensating strategies would be culturally dependent.
You clarified that the target group is fairly homogenous and local, so the strategies are likely to be culturally identical.
A query was raised in relation to the statement that the findings of the study might contribute to modifying current assessment tools to reduce the risk of misdiagnosis - but this is not apparent from the outcome measures and it is not clear how is this will be achieved.
The Committee requested that this is clarified by providing clear outcome measures or removed.

Care and protection of research participants; respect for participants' welfare and dignity; data protection and confidentiality
The Committee discussed the arrangements made to protect privacy through confidentiality as well as the information governance aspects of the study, where and for how long will data be stored, and clarified who will have access to the data.
The Committee queried whether participants would be aware of the fact that they have a social skills problem.
You clarified that evidence from published literature suggests that women with high functioning autism are more aware of their social skills deficit.
Dr Cole added that prospective participants were referred to the service (or requested a referral) due to the social skills deficit; this in itself is not a mental health problem and this group would not have been seen by a mental health team.
A further query was raised in relation to the support offered to participants and to how incidental disclosures would be managed.
You clarified that participants are offered the opportunity to be chaperoned during the interview and in case of disclosures, the duty officer will be contacted. The duty officer would then make a decision how this should be managed and who should be informed.
The Committee requested that the procedure to deal with incidental disclosures and the statutory requirement to break confidentiality is clarified in the protocol and the information given to participants.

Informed Consent process and the adequacy and completeness of participant information
The Committee noted that written informed consent is taken as part of a process - with participants having adequate time to consider the information, and opportunity to ask questions.
The information is clear as to what the participant consents and there is no inducement or coercion. The Committee agreed that the procedures described in the protocol have been adequately addressed in the Information Sheet, but felt that amendments should be made to ensure that individuals understand the information and can make a voluntary informed decision to enrol and continue to participate.

It was noted that the Information Sheet has a number of typographical and grammatical errors and the forming of the documents makes it difficult to read – it was requested that the Information Sheet is proof-read and the following amendments made.
The procedure to deal with incidental disclosures and the statutory duty to breach confidentiality should be elaborated upon in the Information Sheet.
If the intention is to inform the GP this should be clearly discussed in the Information Sheet.
The Welsh language version of the PIS needs to clarify that the interviews will be conducted in English.
The Committee suggested that the lay version of the project title and the aims of the project as described in the information for participants may be rephrased to avoid attaching labels and convening negative values (skills deficit). It could be re-phrased to read, for example "interactions among females with high functioning autism" – this is a suggestion only and not a condition of ethical approval.

Suitability of supporting information
The Committee discussed the suitability of the supporting information and noted that the Interview schedule is leading and assumes that it will find social skills deficit. The Committee requested that potential interview prompts are re-phrased to avoid leading questions.

Other general comments missing information/ typographical errors/ application errors/
The Committee noted that the study documentation has a number of typographical and grammatical errors.

Suitability of the study summary
The summary of the study as it appears in section A6-1 of the REC application form was not deemed to be an accurate description of the study and not suitable for publication on the NRES website. It was noted that the text does not reflect the aim of the study in concordance with the outcome measures and includes unnecessary details (e.g. where the interviews will take place)
The Committee requested that the study summary is re-written to reflect the aims of the study, using lay language. The REC application form should be re-submitted.

The Chairman thanked you and Dr Cole for your availability to speak to this submission and gave you an opportunity to ask questions. You did not raise any issues.
The Chairman confirmed that the Committee will deliberate and will be in touch shortly.

Other ethical issues were raised and resolved in preliminary discussion before your attendance at the meeting.

Based on the information provided, the Committee was satisfied with the following aspects of the research:

- Social or scientific value
- Recruitment arrangements and access to health information, and fair participant selection
- Favourable risk benefit ratio; anticipated benefit/risks for research participants
- Informed consent process
- Suitability of the applicant and supporting staff
- Independent review
- Other general issues

The Committee identified issues with the following aspects of the research:

- Scientific design and conduct of the study
- Care and protection of research participants; respect for participants' welfare and dignity
- Adequacy and completeness of participant information
- Suitability of supporting information
- Suitability of the summary of the research

Documents reviewed

The documents reviewed at the meeting were:

Document	*Version*	*Date*
REC Application Form [REC_Form_01042015]		01 April 2015
Research protocol or project proposal [LSRP Proposal]	1	20 March 2015
Participant information sheet (PIS) [Information Sheet]	1	20 March 2015
Participant consent form [Consent Form]	1	20 March 2015
Interview schedules or topic guides for participants [Interview Questions]	1	20 March 2015
Summary CV for Chief Investigator [Mrs Aimee Jane Hooper]	-	-
Summary CV for supervisor (student research) [Dr Kristina Cole]	-	-
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [UMAL]		01 August 2014

Membership of the Committee

The members of the Committee who were present at the meeting are listed on the attached sheet

No declarations of interest were made in relation to this application

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

15/WA/0142	**Please quote this number on all correspondence**

Yours sincerely

Rossela Roberts

Mr Derek James Crawford, MBChB, FRCS
Chair
E-mail: rossela.roberts@wales.nhs.uk

Enclosure: *List of names and professions of members who were present at the meeting and those who submitted written comments.*

Copy: Sponsor: Mr Hefin Francis
School of Psychology,
Bangor University,
Brigantia Building,
Penrallt Road,
Bangor, Gwynedd, LL57 2AS
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Academic Supervisor: Dr Kristina Cole
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R&D Office: Dr Nefyn Williams
c/o: Miss Debra Slater
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Betsi Cadwaladr University Health Board
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Wales Research Ethics Committee 5
Attendance at Committee meeting on 16 April 2015

Committee Members

Name	*Profession*	*Capacity*	*Present*
Dr. Karen Addy	Clinical Psychologist	Expert	Yes
Dr. Swapna Alexander	Consultant Physician	Expert	Yes
Mrs. Kathryn Chester	Research Nurse	Expert	Yes
Dr. Christine Clark	Consultant Obstetrician & Gynaecologist	Expert	Yes
Dr. Michael Cronin	Consultant Paediatrician (deputy to Dr. Clark)	Expert	No
Mr. Derek James Crawford	Retired Consultant Surgeon (Chair)	Expert	Yes
Mrs. Gwen Dale-Jones	Retired Personal Assistant	Lay +	No
Ms. Geraldine Jenson	Retired College Vice-Principal	Lay +	Yes
Mr. Eliezer Lichtenstein	Student	Lay +	Yes
Dr. Mark Lord	Consultant Pathologist	Expert	Yes
Dr. Pamela Martin-Forbes	NISCHR Research Officer	Expert	No
Dr. Paul Mullins	Reader, MRI Physicist	Lay +	Yes
Mr. Vishwanath Puranik	Associate Specialist ENT Surgeon	Expert	Yes
Mrs. Lynn Roberts	Matron, Emergency Department	Expert	Yes
Mrs. Rachel Roberts-Jones	Student	Lay +	No
Mr. David Alwyn Rowlands	Retired Development & Monitoring Officer	Lay +	Yes
Dr. Jason Walker	Consultant Anaesthetist	Expert	Yes
Dr. Philip Wayman White	General Practitioner (Vice-Chair)	Expert	Yes
Ms. Sydna Ann Williams	Lecturer	Lay +	Yes

In attendance

Name	*Position (or reason for attending)*
Dr. Rossela Roberts	Clinical Governance Officer / RES Manager

Appendix E: Letter in Response to Research Ethics Committee

Dear Dr Crawford,

Study Title:	**A qualitative study looking at the strategies that adult higher functioning women on the autistic spectrum report in order to compensate for and 'mask' social skills difficulties**
REC reference:	**15/WA/0142**
IRAS project:	**169142**

Thank you for your letter dated 17th of April regarding the review of the above project. My supervisor (Dr Kristina Cole) and I have reflected on your recommendations and would like to outline the following clarifications and additional information requested. Please note, that all amendments made to the original documents have been highlighted as requested.

Protocol

1. The 'defining autism' section now includes a working definition of High Functioning Autism for the purpose of the study (please see p. 1). We have also clarified this and details of the diagnostic process in the recruitment section (p. 4)

2. The statement that the study 'will improve diagnostic assessment tools and reduce the risk of under or misdiagnosis' has been removed in the 'research question' section (p.4). This has been done because we are aware that the findings may not have a direct bearing on the current tools used to assess individuals with ASD. We hope however that the insight given may hopefully lead to a more informed assessment process in the future.

3. We have added information to show that all relevant clinical assessments would have been carried out as part of the diagnostic process before being approached for possible engagement in the research (p. 4).

4. We have clarified the procedures with regard to incidental disclosures and statutory requirement to break confidentiality by explaining that participants will be offered the opportunity to be chaperoned during the interview and that this will be clearly stated in the participant information sheet (p. 7-8). In the case of safety concerns, it has now been explained that the duty officer at the local CMHT would be contacted, who would then make a decision as to how this should be managed and who should be informed (p. 7-8). It has been

explained that participants will be informed of this procedure in the participant information sheet (p. 7-8).

Participant Information Sheet

1. We would like to apologize for the typographical and grammatical errors included in the information sheet. This issue has now been addressed.

2. As stated under item 4 protocol, we included the procedures in relation to confidentiality in the proposal and have also changed the participant information sheet accordingly (please see p. 3).

3. The comment "…if you do not want to take part" on 'What will happen next' has been removed (p. 4).

4. We are not contacting participants' GP's as we feel that in the rare instance of incidental disclosures any concerns will be addressed through the duty officer.

5. The information sheet now includes the statement that the interviews will be carried out in English (p. 2).

6. The lay version of the project title has been changed to 'Understanding social skills in female autism'. We felt that the suggested title did not really cover what the study was trying to address, which is social skills (p. 1).

Supporting Information

In response to your helpful feedback, we have looked at the interview schedule and have decided to remove the additional prompt sheets, and the interview questions have also been amended. This has been done to ensure that appropriate lay language is being used, that questions or prompts are not leading in any way, and so that the questions being asked are not negative or assuming of a social skills deficit.

REC application form (IRAS)

Section A6-1 of the REC application has been re-written using lay language and to reflect the aims of the study and avoid unnecessary detail (i.e. interview locations, etc).

Additional Changes

- Changes have been made to the individual who is named as research collaborator who is assisting with recruitment only. Tania Heath, ASD Development worker for Denbighshire County Council is now included on all supporting documents and the IRAS form, rather than the previous collaborator David Oliver who has been

removed due to an ending employment contract. Local Clinical Psychologists employed by the health board in North Wales will now also be assisting with recruitment where necessary, as stated in the relevant supporting documents.

- We have endeavoured to modify the language used in the background information for the study protocol and in all other supporting documents, the aim being to use lay terminology that is suitable for all readers.

- In the research protocol the following additional changes have been made:

  1. The full title of the research has been amended to remove the previous negative term ‘deficits’, as recommended (please see p. 1).

  2. The research question has been amended to remove the aforementioned negative term ‘social skills deficit’ to a more neutral and less assuming question, as recommended (please see p. 4).

  3. All previous use of the terminology ‘social skills deficit’ has been changed throughout the document to ‘social skills difficulties’, to remove the aforementioned negative tone this previous terminology, as recommended.

- In the REC application (IRAS) form the following additional changes have been made:

  1. The short title and version number has been amended to ‘Investigating social skills in female Autism 1’ to remove the negative term ‘deficits’, as recommended.

  2. The full title of the research has been amended to remove the previous negative term ‘deficits’ as recommended to – ‘A qualitative study looking at the strategies that adult high functioning women on the autistic spectrum report in order to compensate for and ‘mask’ social skills difficulties’.

  2. Section ‘A10.’ of the REC application (IRAS) form has been amended to remove the negative term social skills deficit to a more neutral and less assuming question.

  3. Section ‘A12.’ has been amended to use more appropriate lay language, as recommended.

  4. Section ‘A13.’ has been amended to show a working definition of High Functioning Autism as aforementioned above, and also to show the change in research collaborator from Mr David Oliver to Tania Heath, as aforementioned above.

  5. Sections ‘A18’, ‘A27-1.’ and ‘A29.’ have been amended to change research collaborator David Oliver to Tania Heath.

  5. The terminology ‘social skills deficits’ has been changed throughout to ‘social skills difficulties’, for the same reasons as mentioned above.

- In the consent form the following changes have also been made:

1. The lay version of the project title has been changed to ‘Understanding social skills in female autism’ (p. 1).

2. Point ‘1’ has been amended to show new date and version number of the participant information sheet (p. 1).

3. Point ‘5’ has been amended to include the explanation that in the event of incidental disclosure, the researcher will need to contact the duty officer who will decide what to do next and who to contact to ensure the participants and others safety and wellbeing (p. 1).

We would like to thank the Ethics Review committee for the time and effort taken in reviewing this project. The feedback given was highly valuable and has allowed the researcher to improve the overall quality and ethical viability of the study, which will hopefully lead to a stronger proposal and piece of research.

Appendix F: IRAS Form 2 Following Changes

Full Set of Project Data IRAS Version 5.3.0

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please complete the questions in order. If you change the response to a question, please select 'Save' and review all the questions as your change may have affected subsequent questions.

Please enter a short title for this project (maximum 70 characters)
Investigating social skills in female Autism 1

1. Is your project research?

(•) Yes ( ) No

2. Select one category from the list below:

( ) Clinical trial of an investigational medicinal product

( ) Clinical investigation or other study of a medical device

( ) Combined trial of an investigational medicinal product and an investigational medical device

( ) Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice

( ) Basic science study involving procedures with human participants

( ) Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology

(•) Study involving qualitative methods only

( ) Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)

( ) Study limited to working with data (specific project only)

( ) Research tissue bank

( ) Research database

If your work does not fit any of these categories, select the option below:

( ) Other study

2a. Please answer the following question(s):

a) Does the study involve the use of any ionising radiation? ( ) Yes (•) No

b) Will you be taking new human tissue samples (or other human biological samples)? ( ) Yes (•) No

c) Will you be using existing human tissue samples (or other human biological samples)? ( ) Yes (•) No

3. In which countries of the UK will the research sites be located? *(Tick all that apply)*

[ ] England
[ ] Scotland

- [x] Wales
- [ ] Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

- ○ England
- ○ Scotland
- ◉ Wales
- ○ Northern Ireland
- ○ This study does not involve the NHS

4. Which applications do you require?

IMPORTANT: If your project is taking place in the NHS and is led from England select 'IRAS Form'. If your project is led from Northern Ireland, Scotland or Wales select 'NHS/HSC Research and Development Offices' and/or relevant Research Ethics Committee applications, as appropriate.

- [ ] IRAS Form
- [x] NHS/HSC Research and Development offices
- [ ] Social Care Research Ethics Committee
- [x] Research Ethics Committee
- [ ] Confidentiality Advisory Group (CAG)
- [ ] National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D Offices in Northern Ireland, Scotland and Wales the CI must create NHS/HSC Site Specific Information forms, for each site, in addition to the study wide forms, and transfer them to the PIs or local collaborators.

For participating NHS organisations in England different arrangements apply for the provision of site specific information. Refer to IRAS Help for more information.

5. Will any research sites in this study be NHS organisations?

◉ Yes ○ No

6. Do you plan to include any participants who are children?

○ Yes ◉ No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

○ Yes ◉ No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the Confidentiality Advisory Group to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

○ Yes ◉ No

9. Is the study or any part of it being undertaken as an educational project?

(●) Yes ( ) No

Please describe briefly the involvement of the student(s):
The student is a trainee Clinical Psychologist who is conducting the research (interviews with the participants and qualitative analysis of the interview content) for her third year research project/thesis in order to qualify as a clinical psychologist.

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

(●) Yes ( ) No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

( ) Yes (●) No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

( ) Yes (●) No

Full Set of Project Data IRAS Version 5.3.0

Integrated Research Application System
Application Form for Research involving qualitative methods only

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting Help.

Please define any terms or acronyms that might not be familar to lay reviewers of the application.

Short title and version number: (maximum 70 characters - this will be inserted as header on all forms)
Investigating social skills in female Autism 1

PART A: Core study information

1. ADMINISTRATIVE DETAILS

A1. Full title of the research:

A qualitative study looking at the strategies that adult high functioning women on the autistic spectrum report in order to compensate for and 'mask' social skills difficulties.

A2-1. Educational projects

Name and contact details of student(s):

Student 1

Title	Forename/Initials	Surname
Mrs	Aimee Jane	Hooper

Address	Llys Owen, Maes Ogwen, Tregarth, Bangor, Gwynedd, North Wales
Post Code	LL57 4PH
E-mail	psp2ce@bangor.ac.uk
Telephone	07826062415
Fax	

Give details of the educational course or degree for which this research is being undertaken:

Name and level of course/ degree:
Doctorate in Clinical Psychology (DClinPsy)

Name of educational establishment:
Bangor University, North Wales

Name and contact details of academic supervisor(s):

Academic supervisor 1

Title	Forename/Initials	Surname
Dr	Kristina	Cole

Address	Roslin CMHT, Nant y Gamar Road

Full Set of Project Data IRAS Version 5.3.0

	Craig y Don, Llandudno, Conwy
Post Code	LL30 1YE
E-mail	kristina.cole@wales.nhs.uk
Telephone	01492 860926
Fax	

Please state which academic supervisor(s) has responsibility for which student(s):
Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.

Student(s)	Academic supervisor(s)
Student 1 Mrs Aimee Jane Hooper	☑ Dr Kristina Cole

A copy of a current CV for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.

A2-2. Who will act as Chief Investigator for this study?

- (•) Student
- ( ) Academic supervisor
- ( ) Other

A3-1. Chief Investigator:

Title	Forename/Initials	Surname
Mrs	Aimee Jane	Hooper

Post	Trainee Clinical Psychologist
Qualifications	BSc Applied Psychology of First Class Honours
Employer	North Wales Clinical Psychology Programme & BCUHB
Work Address	School of Psychology, Brigantia Building, Bangor University, Bangor, Gwynedd North Wales
Post Code	LL57 2DG
Work E-mail	psp2ce@bangor.ac.uk
* Personal E-mail	
Work Telephone	01248 388365
* Personal Telephone/Mobile	07826062415
Fax	

** This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.*
A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.

A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?
This contact will receive copies of all correspondence from REC and HRA/R&D reviewers that is sent to the CI.

Title	Forename/Initials	Surname
Mr	Hefin	Francis

Full Set of Project Data IRAS Version 5.3.0

Address	School of Psychology Bangor University, Bangor, Gwynedd
Post Code	LL7 2AS
E-mail	h.francis@bangor.ac.uk
Telephone	01248388339
Fax	

A5-1. Research reference numbers. *Please give any relevant references for your study:*

Applicant's/organisation's own reference number, e.g. R & D (if available):

Sponsor's/protocol number:

Protocol Version:

Protocol Date:

Funder's reference number:

Project website:

Additional reference number(s):

Ref.Number Description	Reference Number

Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you have registered your study please give details in the "Additional reference number(s)" section.

A5-2. Is this application linked to a previous study or another current application?

○ Yes ◉ No

Please give brief details and reference numbers.

2. OVERVIEW OF THE RESEARCH

To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.

A6-1. Summary of the study. *Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments' Research Ethics Service, this summary will be published on the Health Research Authority (HRA) website following the ethical review. Please refer to the question specific guidance for this question.*

To date there is minimal research that has attempted to specifically ask women with high functioning autism (HFA) exactly what it is they do to cope in social situations and what age they may have first started noticing they were different from their peers. There is also minimal research that has attempted to ask what might have motivated them to hide possible difficulties in social interactions, and how and from whom they may have developed or learned strategies to help them cope in social situations.
The purpose of the current qualitative study is to try and address this much needed area of research by attempting to answer the following question - 'What strategies and techniques may females with high functioning Autism (HFA) be using in order to cope in social situations, and when, how and why might they do this?' Such research might aid our understanding of how females with HFA present which may help to reduce the number of females with HFA who go unnoticed or misdiagnosed in the future.
The current study will try to attempt to answer this research question by recruiting and interviewing eight English

speaking HFA adult women (N = 8), aged 19 – 60 years, with a current diagnosis of ASD or Asperger syndrome. Prior to being invited to the interviews the participants would have already received their diagnosis, and any indicators of low intellectual functioning or learning difficulty indicative of more severe impairment would have been ruled out during the comprehensive clinical assessment process. All eight semi-structured interviews will be transcribed and qualitatively analysed through Applied Thematic Analysis.

A6-2. Summary of main issues. *Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.*

Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, R&D office or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.

Risk to participants

The risk to participant may be if the participant becomes distressed during the interview and/or if they disclose information that is of serious and immediate concern (i.e. self-harm, suicidal plans or abuse). To reduce any possible distress during interview, the questions asked will be carefully constructed so to not provoke distress or be too difficult for a participant to answer.

Participants will be allowed to bring a supportive other with them to the interview if they so wish for support, who would wait in the reception area. This will be clearly explained to participants in their information sheet prior to attending their interview. The participants could then seek support from this person should they so wish at any time during the interview should they want to stop or take a break. All interviews will be conducted in an empathetic and highly professional manner, showing respect and consideration for the participants' welfare and needs. Participants will be reminded of their free will to stop, leave or take a break.

If the participant was to disclose information of a serious concern to their own or others safety and wellbeing, the researcher will support the participant in reducing any emotional distress they may be experiencing. The researcher will also discuss possible next options/steps with the participant. The duty officer of the local Community Mental Health Team (CMHT) would then be consulted for further guidance who would then decide on what should be done and who should be informed. In the unlikely instance that the participant would need emergency assistance, the emergency services would be called by the researcher.

Risk to researcher

The risk to researcher will involve the risk of lone working when conducting the interviews. In order to reduce the risk and ensure safety of the researcher, the NHS Betsi Cadwaladwr lone worker policy will be followed, with recording from a known base and informing the research supervisor of the interview diary/ schedule, and stating the researcher's whereabouts and expected time of return.

Data Storage

The interview data will be recorded on an NHS/NCWPP digital audio recorder, which will be safely stored in a secure locked filing cabinet on NHS/NWCPP premises. Data which has been transcribed on a password protected computer will be stored safely on a password protected and encrypted memory stick which will also be safely stored in a secure locked filing cabinet on NHS/ NWCPP premises.

A6-3. Proportionate review of REC application *The initial project filter has identified that your study may be suitable for proportionate review by a REC sub-committee. Please consult the current guidance notes from NRES and indicate whether you wish to apply through the proportionate review service or, taking into account your answer to A6-2, you consider there are ethical issues that require consideration at a full REC meeting.*

◯ Yes - proportionate review ◉ No - review by full REC meeting

Further comments (optional):

Note: This question only applies to the REC application.

3. PURPOSE AND DESIGN OF THE RESEARCH

A7. Select the appropriate methodology description for this research. *Please tick all that apply:*

- ☐ Case series/ case note review
- ☐ Case control
- ☐ Cohort observation
- ☐ Controlled trial without randomisation
- ☐ Cross-sectional study
- ☐ Database analysis
- ☐ Epidemiology
- ☐ Feasibility/ pilot study
- ☐ Laboratory study
- ☐ Metanalysis
- ☑ Qualitative research
- ☑ Questionnaire, interview or observation study
- ☐ Randomised controlled trial
- ☐ Other (please specify)

A10. What is the principal research question/objective? *Please put this in language comprehensible to a lay person.*

"What strategies or techniques may females with high functioning Autism (HFA) be using in order to cope in social situations, and when, how and why might they do this?"

A11. What are the secondary research questions/objectives if applicable? *Please put this in language comprehensible to a lay person.*

1. What age they first started noticing they were different from their peers?
2. What motivated them to camouflage social skills difficulties?
3. How and from whom have they developed or learned such skills/ techniques?

A12. What is the scientific justification for the research? *Please put this in language comprehensible to a lay person.*

Due to the suggestions that males and females with high functioning autism (HFA) may differ in how they present, some researchers have argued that this may in part be due to the diagnostic assessments and tools used to diagnose ASD, which many propose are 'male biased' and geared towards a stereotypically male orientated understanding of autism (Kirkovski et al., 2013). Similarly there seems to be anecdotal evidence from clinicians working in the Autism field to suggest that females may be receiving diagnoses later on in adolescence and adulthood. This has led to further debates as to whether the aforementioned 4.3:1 sex ratio is a true reflection of its prevalence in females.

Due to findings implying that females with HFA may be being undiagnosed, misdiagnosed or diagnosed later on in life due to being 'missed', it begs the question as to why and how this is occurring. Is it due to the aforementioned 'male bias' in the clinical understanding and assessment of ASD? Or is it conversely (or additionally) due to females using specific techniques and strategies that allow them to go unnoticed in comparison to their male counterparts? The latter is a research area which is slowly receiving increased attention and will be the focus of the present investigation.

Gender

There is evidence to suggest that HFA affects more males than females, with a suggested male to female ratio of 4.3: 1 (Lai et al., 2011). This sex imbalance has been seen from the very beginning of the research literature (Kanner, 1943). Although there is evidence to suggest that males and females on the autistic spectrum are similar in certain areas, the need for further research into the potential gender differences across the spectrum has been highlighted. A better understanding of gender differences seen in individuals with HFA would not only aid our understanding of females with HFA but also our understanding of the autistic spectrum itself (Attwood, 2007).

Researchers are now investigating whether there are genetic differences between males and females with HFA, with evidence to suggest gender differences with regards to the type of restrictive or repetitive behaviours and interests shown, executive functioning abilities, empathising abilities, socio-communicative skills and how they react to being different from their peers (Cridland, Jones, Caputi & Magee, 2014; Kirkovski, Enticott & Fitzgerald, 2013; Lai et al. (2011); Van Wijngaarden-Cremers et al., 2014). In a review of 113 papers, Kirkovski et al. (2013) found that 78.8% of the studies provided support for a differing profile for females with HFA.

Due to the suggestions that males and females with HFA differ in how they present, some researchers have argued that this may in part be due to the diagnostic assessments and tools used to diagnose ASD, which many propose are 'male biased' and geared towards a stereotypically male orientated understanding of autism (Kirkovski et al., 2013). Similarly there seems to be anecdotal evidence from clinicians working in the Autism field to suggest that females may be receiving diagnoses later on in adolescence and adulthood. This has led to further debates as to whether the aforementioned 4.3:1 sex ratio is a true reflection of its prevalence in females.

It has also been proposed that females' HFA traits may also be hidden by having special interests in areas that are typically non-male such as fashion, animals, nature, or another particular interest in the realm of social interaction, making these special interests harder to detect (Attwood, 2007). This is in comparison to the male-typical special interests observed in HFA such as automobiles, history, sports, engineering, trains, etc.

Due to findings implying that females with HFA may be being undiagnosed, misdiagnosed or diagnosed later on in life due to being 'missed', it begs the question as to why and how this is occurring. Is it due to the aforementioned 'male bias' in the clinical understanding and assessment of ASD? Or is it conversely (or additionally) due to females using specific techniques and strategies that allow them to go unnoticed in comparison to their male counterparts? The latter is a research area which is slowly receiving increased attention and will be the focus of the present investigation.

Superficial Sociability

There is evidence to suggest that one of the reasons why females with HFA may be 'missed' with regards to a diagnosis of ASD, is due to their abilities in 'masking' or 'camouflaging' possible social skills difficulties in the social arena (Atwood, 2007).

Lai et al. (2011) found that adult women with HFA presented with fewer socio-communication impairments in comparison to adult men, and also self-reported more autistic traits than males, suggesting a possible heightened awareness of their difficulties. Therefore, if females are more aware of their difficulties, they may make more efforts than males to try to be accepted by others, to 'fit in' or conversely, to go unnoticed. Müller, Schuler, & Yates (2008) also found that adults with HFA aged 18-62 years described the experience of having to navigate the social arena as isolating and challenging, which led some participants to observe and model the behaviour of their peers, siblings or colleagues in order to superficially present as 'socially skilled'. However, this was minimally addressed in this paper, and only 5 of the 18 participants were female, therefore the results may not be generalizable to the female HFA population as a whole.

There are findings that suggest that females are better at pretend play and social imitation than males in childhood, which result in their underlying social skills deficits being masked (Attwood, 2007; Cridland et al.,2014; Solomon et al., 2012), until adolescence or early adulthood where changes in relationship complexities and social environments challenge and strain their abilities to continue to camouflage and mask. Due to the possible imitation of social behaviour, parents of HFA daughters have reported finding the diagnostic process challenging, due to clinicians being hesitant in committing to giving a formal diagnosis (Cridland et al., 2014).

Evidence of females potentially masking social skills difficulties in the social arena are also evidenced across the media in radio interviews, autobiographies and self-help books for females with HFA. For example, Temple Grandin (1992) openly describes how she avidly observed human behaviour, and achieved social success through rote learning of how to act in different situations, using certain 'social scripts' she recalled from previous conversations. The author of the popular novel 'Pretending to be normal: Living with Asperger's Syndrome' Liane Willey (1999) also describes how she would camouflage her social confusion by acting out different 'personas' created from famous icons or people she knew, by mimicking their speech, phrases, clothing and body language. She also recalls hiding on the periphery of groups in order to go unnoticed (Willey, 1999).

Gaps in the literature

The question with regards to how and why females may be masking and camouflaging their socio-communicative difficulties in the social arena still remains inadequately addressed in the literature. Some suggest that females with HFA may experience more pressure and expectation to be empathetic, sensitive and develop friendships that rely heavily on reciprocity and communication than their male counterparts (Kopp & Gillberg, 1992).

A potentially increased awareness of their differences from their non-autistic peers may drive them to consciously or unconsciously mask their difficulties through means of imitation, acting or using certain techniques in order to go unnoticed. Some females may try to avoid being the centre of attention, by being quietly behaved and being overly apologetic or passive (Attwood, 2007).

However, to date there is minimal research that has attempted to specifically ask women with HFA exactly what it is they do to present as superficially skilled in social situations; what age they first started noticing they were different from their peers; what motivated them to camouflage their social skills difficulties, and how and from whom they developed or learned such techniques.

Such research might aid our understanding of how females with HFA present which may help to reduce the number of females with HFA who go unnoticed or misdiagnosed in the future.

A13. Please summarise your design and methodology. *It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.*

Participants

The consenting participants will be eight HFA adult women (N = 8) with a current diagnosis of ASD or Asperger syndrome, whom prior to being invited would have already received their diagnosis, and any indicators of low intellectual functioning or learning difficulty indicative of more severe impairment would have been ruled out during the comprehensive clinical assessment process. Participants would need to be able to communicate in English and be aged between 19-60 years.

Recruitment

Participants will be recruited through local BCUHB Clinical Psychologists currently working with this client group. Participants may also be recruited through professional connections with ASD Development Worker Tania Heath who is employed by Denbighshire County Council. It is already known that the approximate number of individuals who can be contacted via these key professional sources may be up to 30 individuals, which would comfortably allow for the average 40% response rate to research recruitment seen in other studies.

Recruitment will be conducted through the support of the above professionals, who would provide support to contact potential participants (who meet the exclusion/inclusion criteria) by telephone or face-to-face communications to see if they would be interested in taking part in the study. Verbal interest in the study would lead to the potential participant being sent an A4 information pack by post by researcher Aimee Hooper.

This A4 information pack would include a participant information sheet and return slip with pre-paid envelope enclosed, for participants who are interested and wish to take part in the study and give consent for the researcher to contact them by post or telephone to schedule an interview appointment.

Design and Procedures

Consenting participants will be invited to a semi-structured interview with researcher Aimee Hooper at a mutually agreed time and location (i.e. Bangor University North Wales Clinical Psychology Programme (NWCPP) or Roslin Community Mental Health Team). The researcher will take into consideration the participants' ability to travel and the distance of their home or work address from these locations when arranging interview appointments. Participants will be refunded their travel expenses for the interview up to a maximum cost of £18.00.

The interview will last for approximately 60 minutes, during which participants will be asked semi-structured questions with some set prompts if required.

Consent forms (addressing informed consent, confidentiality and consent for the interviews to be audio recorded) will be discussed with and given to the participant before commencing the audiotaped interview. Participants will be adequately informed that they can ask questions, have a break, stop or refuse to answer any questions should they feel the need to. Refreshments will be made available in the interview room.

Measures

Some of the demographic data to be collected for each group will be as follows:
- Age
- Marital Status
- Employment Status

• Age of formal diagnosis of autism

Data Storage

The interview data will be recorded on an NHS/NCWPP digital audio recorder, which will be safely stored in a secure locked filing cabinet on NHS/NWCPP premises. Data which has been transcribed onto a computer will be stored safely on a NHS/NWCPP password protected memory stick which will also be stored in a secure locked filing cabinet on NHS/NWCPP premises.

Analysis

Due to the qualitative nature of the data the transcribed interviews will be analysed using the qualitative method of Applied Thematic Analysis (ATA; Guest, MacQueen & Namey, 2012). ATA is highly credible and would allow the trainee to identify and examine themes from the interview data in a systematic, efficient and ethical way that would facilitate transparency of the methods and procedures used (Guest et al., 2012). ATA would also support the demonstration of methodological and analytic rigour for a VIVA.

The aforementioned research question is suitable for this form of analysis, as well as the proposed sampling and data collection methods. A sample size of 8 participants is an acceptable sample size for ATA. Semi-structured interviews work well with ATA as they are objective collections of the participants' lived story – "words will speak for themselves..." (Starks & Trinidad, 2007). The use of probing questions and prompts will therefore be appropriate for ATA, in order to encourage the participants to elaborate when necessary. Relevant literature, manuals and online resources will be accessed.

All interviews will be carried out first, and then each interview will be analysed and coded in order of the date in which they were conducted. With regards to the presentation of the findings, they may be presented diagrammatically.

The audience for this piece of research is appropriate and representative of the audiences usually aimed at by ATA – clinicians, researchers and other professionals.

A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

- ☐ Design of the research
- ☐ Management of the research
- ☐ Undertaking the research
- ☐ Analysis of results
- ☐ Dissemination of findings
- ☑ None of the above

Give details of involvement, or if none please justify the absence of involvement.

4. RISKS AND ETHICAL ISSUES

RESEARCH PARTICIPANTS

A15. What is the sample group or cohort to be studied in this research?

Select all that apply:

- ☐ Blood
- ☐ Cancer
- ☐ Cardiovascular
- ☐ Congenital Disorders
- ☐ Dementias and Neurodegenerative Diseases

Intervention or procedure	1	2	3	4
Approached regarding the research	1	0	15 mins	Research supervisor Dr Kristina Cole from Roslin CMHT or Research Collaborator Tania Heath, ASD worker for Denbighshire County Council - via telephone or face-to-face discussion
Receive information sheets in an A4 pack	1	0	20 mins	To be sent by researcher Aimee Hooper to address of the potential participants for them to read and decide if they would like to take part.
Give request and consent to participate	1	0	15 mins	Participant to reply using pre-paid stamped envelope only if agreeing to participate with written signed consent to taking part in the research.
Give consent to being audiotaped during interview	1	0	10 mins	Researcher Aimee Hooper to request and gain written signed consent from participant to having interview audio recorded before conducting interview, at interview location.
Explaining confidentiality and the limits of this	1	1	10 mins	Researcher Aimee Hooper to explain confidentiality and the limits of this before proceeding with interview, at interview location.
Research interview	1	0	60-80 mins	Researcher Aimee Hooper to conduct interview with participant at chosen interview location - either Roslin CMHT; or Bangor University.
Dissemination of research results	1	0	15	Report of the results will be sent to participant by researcher Aimee Hooper to participants address, unless they specifically ask to not be contacted after the interview. Results would be sent in stamped envelope addressed only to the participant, marked as 'private & confidential'.

A21. How long do you expect each participant to be in the study in total?

From being sent the information sheet to being sent results of the research findings, participants will be involved in the study on some level for a maximum of 19 months. However, participants will only actually be actively involved in the research process for approximately 3 hours in total.

A22. What are the potential risks and burdens for research participants and how will you minimise them?

For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.

Risk to participants

The risk to participant may be if the participant becomes distressed during the interview and/or if they disclose information that is of serious and immediate concern (i.e. self-harm, suicidal plans or abuse). To reduce any possible distress during interview, the questions asked will be carefully constructed so to not provoke distress or be too difficult for a participant to answer.

Participants will be allowed to bring a supportive other with them to the interview if they so wish for support, who would wait in the reception area. This will be clearly explained to participants in their information sheet prior to attending their interview. The participants could then seek support from this person should they so wish at any time during the interview should they want to stop or take a break. All interviews will be conducted in an empathetic and highly professional manner, showing respect and consideration for the participants' welfare and needs. Participants will be reminded of their free will to stop, leave or take a break.

If the participant was to disclose information of a serious concern to their own or others safety and wellbeing, the researcher will support the participant in reducing any emotional distress they may be experiencing. The researcher will also discuss possible next options/steps with the participant. The duty officer of the local CMHT would then be

consulted for further guidance who would then decide on what should be done and who should be informed. In the unlikely instance that the participant would need emergency assistance, the emergency services would be called by the researcher.

Data Storage

The interview data will be recorded on an NHS/NCWPP digital audio recorder, which will be safely stored in a secure locked filing cabinet on NHS/NWCPP premises. Data which has been transcribed on a password protected computer will be stored safely on a password protected and encrypted memory stick which will also be stored in a secure locked filing cabinet on NHS/NWCPP premises.

A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?

(●) Yes ( ) No

If Yes, please give details of procedures in place to deal with these issues:

To reduce any possible distress during interview, the questions asked will be carefully constructed so to not provoke distress or be too difficult for a participant to answer. All interviews will be conducted in an empathetic and highly professional manner, showing full respect and consideration for the participants' welfare and needs throughout and the participant will be reminded of their free will to stop, leave or take a break should they so wish, or speak to a supportive companion if they came accompanied.
The participant will be supported in grounding themselves and work on reducing their distress before they leave the building.
If the client was to disclose information of a serious concern to their own or others safety and wellbeing, the researcher will support the participant and help them to reduce any emotional distress they may be experiencing. The researcher will also discuss possible next options/steps with the participant. The local duty officer would then be consulted for further guidance who would then decide on what should be done and who should be informed. In the highly unlikely instance that the participant would need emergency assistance, the emergency services would be called by the researcher.

A24. What is the potential for benefit to research participants?

We cannot promise the study will help participants, but the information we get from the study may help to increase the understanding, diagnosis and treatment of women with Autism. The participants may also gain a positive and validating experience from being listened to and given an opportunity to have their voice heard, with the knowledge that it is contributing to psychological research.

A26. What are the potential risks for the researchers themselves? *(if any)*

The risk to researcher will involve the risk of lone working when conducting the interviews. In order to reduce the risk and ensure safety of the researcher, the BCUHB lone working policy will be followed, with recording from a known base, and stating the researcher's whereabouts and expected time of return.

RECRUITMENT AND INFORMED CONSENT

In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.

A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used? *For example, identification may involve a disease register, computerised search of social care or GP records, or review of medical records. Indicate whether this will be done by the direct care team or by researchers acting under arrangements with the responsible care organisation(s).*

Dr Kristina Cole and Tania Heath (ASD Development Worker) have been informed about the study and have agreed to identify potential participants, using the provided inclusion and exclusion criteria that will at the required time be given to them by the researcher Aimee Hooper. They will discuss the research with the potential participant, and if the individual wishes to know more about the research, the researcher will be notified of the potential participants who will then be sent the information sheet and consent forms in a pack through the post in a sealed brown envelope marked as private and confidential, and addressed only to that person.

A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?

○ Yes ◉ No

Please give details below:

A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?

○ Yes ◉ No

A29. How and by whom will potential participants first be approached?

Potential participants will first be approached by either Dr. Kristina Cole or Tania Heath, who will briefly tell them about the research to see if they would like to know more about it or consider taking part.
Those who express an interest will be sent an A4 information pack in the post by Aimee Hooper.

A30-1. Will you obtain informed consent from or on behalf of research participants?

◉ Yes ○ No

If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.

If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.

All participants willing to take part in the study will be asked to complete a consent form, which will be provided in the initial information pack, requiring the participant to answer some essential questions and provide a written signature to declare they are agreeing to take part.
Participants will also be asked for their consent for direct quotations to be used from the recording of the interviews if selected.
Participants will also be asked for their preferred address or telephone contact number (i.e. mode of contact) for the researcher to contact them on in the future, so to arrange the interview date and time.

Also, in the information pack participants will be made aware that as a part of the study, the interviews will be audio recorded in order to gather the qualitative data that the research question requires. On the day of the interview the participant will be reminded that the interview will be audio recorded and asked for their consent for the interview to be recorded, before the researcher is able to conduct the interview.

If you are not obtaining consent, please explain why not.

Please enclose a copy of the information sheet(s) and consent form(s).

A30-2. Will you record informed consent (or advice from consultees) in writing?

◉ Yes ○ No

A31. How long will you allow potential participants to decide whether or not to take part?

Two weeks

A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs? *(e.g. translation, use of interpreters)*

As part of the inclusion criteria, only participants who can speak English will be included in the study. The reasons for this are justifiable, as the researcher does not speak Welsh, and therefore would not be able to conduct the interviews through the medium of welsh, and a translator would not be available during interviews as it would not be covered by the limited budget and time provided to conduct the research. Participants will be clearly informed of this in the participant information sheet.

However, all information sheets and consent forms will not only be provided in English but will also be translated into the medium of Welsh.

A33-2. What arrangements will you make to comply with the principles of the Welsh Language Act in the provision of information to participants in Wales?

All information sheets and consent forms will not only be provided in English but will also be translated into the medium of Welsh and provided to the participants. However, the interviews will not be conducted in the welsh language and and a translator would not be available as it would not be covered by the limited budget and time available to conduct the research.

A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? *Tick one option only.*

- ○ The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.
- ◉ The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.
- ○ The participant would continue to be included in the study.
- ○ Not applicable – informed consent will not be sought from any participants in this research.
- ○ Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

Further details:

If the data has already been collected, then as a sign of respect to the participant and the time they gave to the study, their data will still be used for analysis.
Upon completing the study, it will be recorded that the participant lost capacity to provide informed consent and this record will be kept, but the data will not be made available to the research team after this stage.

If you plan to retain and make further use of identifiable data/tissue following loss of capacity, you should inform participants about this when seeking their consent initially.

CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

Storage and use of personal data during the study

A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)? *(Tick as appropriate)*

- ☐ Access to medical records by those outside the direct healthcare team
- ☐ Access to social care records by those outside the direct social care team
- ☐ Electronic transfer by magnetic or optical media, email or computer networks
- ☐ Sharing of personal data with other organisations
- ☐ Export of personal data outside the EEA
- ☑ Use of personal addresses, postcodes, faxes, emails or telephone numbers

- [x] Publication of direct quotations from respondents
- [ ] Publication of data that might allow identification of individuals
- [x] Use of audio/visual recording devices
- [ ] Storage of personal data on any of the following:
  - [ ] Manual files (includes paper or film)
  - [ ] NHS computers
  - [ ] Social Care Service computers
  - [ ] Home or other personal computers
  - [ ] University computers
  - [ ] Private company computers
  - [ ] Laptop computers

Further details:
Information sheets and reply slip in a pack will be sent to the interested potential participants.
Those who agree to participate will be asked for their preferred mode of contact (i.e. address or telephone number) for the researcher to contact them on to arrange the interview time, date and location.
This means addresses and/or telephone numbers of participants will only be provided to the researcher by those wishing to participate in the study, and completed forms will be kept in a secure locked cabinet on BCUHB/ NWCPP premises.

Direct quotations may be published in the written research report, which will be clearly explained in the information sheet and participants will be asked for their consent on this on the consent form. Direct quotations will not be used for participants who do not give consent.

All interviews will need to be digitally recorded. This recording will be conducted using an NWCPP digital audio recorder which will be kept on Bangor University (NWCPP)/ BCUHB (Roslin CMHT) premises in a locked cabinet, accessed by only the researcher. The recorded interviews will be transferred onto an encrypted BCUHB/NWCPP USB stick for analysis and used on a password protected laptop, but recordings and files containing transcriptions will only be stored and saved on the encrypted USB stick, not on any other device.

A37. Please describe the physical security arrangements for storage of personal data during the study?

The audio digital recorder, USB stick and completed consent forms will be stored in a secure locked filing cabinet on BCUHB (Roslin CMHT)/ NWCPP (Bangor University) premises which only the researcher Aimee Hooper will have access to. Once the interviews have been completed, the consent forms will be placed in the participants clinical file by Aimee Hooper. The encrypted USB stick will have a password known only by the researcher. Audio recordings and transcriptions will only be saved on the USB stick.

A38. How will you ensure the confidentiality of personal data? *Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.*

All personal data about participants (i.e. names, places, and specific information)
will be anonymous on transcripts to prevent identification - each participant will be given a participant number. The researcher will follow the policy and guidance of the Data Protection Act (1998) and the codes of practice for confidentiality, information governance and information security. The audio digital recorder, consent forms, and encrypted USB stick will be stored in a secure locked filing cabinet on BCUHB/ NWCPP premises, accessible by only the researcher and the encrypted USB stick will have a password known only by the researcher.

A40. Who will have access to participants' personal data during the study? *Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.*

The researcher Aimee Hooper will require the address/ telephone number of all consenting participants in order to make contact to arrange the interview location, date and time. Consent forms with the above information on will be filed in a secure locked cabinet on BCUHB/ NWCPP premises. Once the interviews have been completed the consent forms will be placed in the participants clinical file by Aimee Hooper.

Storage and use of data after the end of the study

A41. Where will the data generated by the study be analysed and by whom?

The research interviews will be transcribed and analysed by researcher Aimee Hooper, who will be conducting the analysis on BCUHB/ NWCPP premises.

A42. Who will have control of and act as the custodian for the data generated by the study?

	Title	Forename/Initials	Surname
	Mrs	Aimee	Hooper
Post	Trainee Clinical Psychologist		
Qualifications	BSc Applied Psychology - First Class Honours.		
Work Address	North Wales Clinical Psychology Programme (NWCPP),		
	Department of Psychology,		
	43 College Road, Bangor, Gwynedd		
Post Code	LL57 2DG		
Work Email	psp2ce@bangor.ac.uk		
Work Telephone	01248382205		
Fax			

A43. How long will personal data be stored or accessed after the study has ended?

- (●) Less than 3 months
- ( ) 3 – 6 months
- ( ) 6 – 12 months
- ( ) 12 months – 3 years
- ( ) Over 3 years

A44. For how long will you store research data generated by the study?

Years: 3
Months: 0

A45. Please give details of the long term arrangements for storage of research data after the study has ended. *Say where data will be stored, who will have access and the arrangements to ensure security.*

Research data (i.e. anonymous interview recordings) on the encrypted USB stick will be handed over to NWCPP Bangor University as a requirement of the researcher's clinical training, for it to be stored in a secure locked cabinet. After 3 years the USB stick will be wiped and any data on the stick will therefore be destroyed of safely and securely.

INCENTIVES AND PAYMENTS

A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?

(●) Yes ( ) No

If Yes, please give details. For monetary payments, indicate how much and on what basis this has been determined.
Participants will have their expenses for travelling to the interview reimbursed up to a total of £18.00 on the day of the interview, which will be funded by NWCPP Bangor University. The travel expenses will be reimbursed to the participant upon arrival to the interview before the interview takes place to reduce any anxieties or stress the participant may have about this, so not to impact on the interview process.

A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?

○ Yes ◉ No

A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?

○ Yes ◉ No

NOTIFICATION OF OTHER PROFESSIONALS

A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?

○ Yes ◉ No

If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.

PUBLICATION AND DISSEMINATION

A50-1. Will the research be registered on a public database?

○ Yes ◉ No

Please give details, or justify if not registering the research.
This research will not be registered on a public database, as it will not be publicly funded. However, a paper copy of the Doctoral Thesis will be kept on file and securely stored in the library at Bangor University.

Registration of research studies is encouraged wherever possible.
You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you are aware of a suitable register or other method of publication, please give details. If not, you may indicate that no suitable register exists. Please ensure that you have entered registry reference number(s) in question A5-1.

A51. How do you intend to report and disseminate the results of the study? *Tick as appropriate:*

- [x] Peer reviewed scientific journals
- [ ] Internal report
- [x] Conference presentation
- [ ] Publication on website
- [ ] Other publication
- [ ] Submission to regulatory authorities
- [ ] Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators

☐ No plans to report or disseminate the results
☐ Other (please specify)

A52. If you will be using identifiable personal data, how will you ensure that anonymity will be maintained when publishing the results?

All interviews will be anonymised and participants will be given a participant number so not to use any personal identifiers, and any direct quotes used in the scientific report and in publication will also be anonymous with no personal identifiers left in, and only used with the participants consent to do so.

A53. Will you inform participants of the results?

◉ Yes ○ No

Please give details of how you will inform participants or justify if not doing so.
Participants will be asked at the end of the interview if they would like to be contacted again by letter with information on the results of the study, which would be in a stamped brown envelope addressed only to the participant, marked as private and confidential.
Participants who do not wish to be contacted again after the interviews with the results will not be contacted, in respect of their request.

5. Scientific and Statistical Review

A54-1. How has the scientific quality of the research been assessed? *Tick as appropriate:*

☐ Independent external review
☐ Review within a company
☐ Review within a multi−centre research group
☑ Review within the Chief Investigator's institution or host organisation
☑ Review within the research team
☑ Review by educational supervisor
☐ Other

Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:
A detailed research proposal has been submitted, checked and approved by the research team at NWCPP, Bangor University. The Bangor University Psychology Ethics board has also approved the research project at the time of submitting this form.

For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.

For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.

A59. What is the sample size for the research? *How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.*

Total UK sample size:	8
Total international sample size (including UK):	8
Total in European Economic Area:	0

Further details:
Due to the qualitative methodology and data analysis involved in this study, a sample size of 8 participants was deemed most appropriate to fit in with the available time scale and resources available to the researcher.

A60. How was the sample size decided upon? *If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.*

A minimum of 4 and maximum of 10 participants is generally recommended when analyzing qualitative interview data on a limited time frame, mainly due to the time consuming nature of coding and analyzing the interviews - it takes on average ten hours to code and analyse one hour of an interview. Therefore 8 was deemed a reasonable sample size that would provide the researcher with enough time to conduct the analyses without having a sample size that is too small.

A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.

Due to the qualitative nature of the data the transcribed interviews will be analysed using the qualitative method of Applied Thematic Analysis (ATA; Guest, MacQueen & Namey, 2012). ATA is highly credible and would allow the trainee to identify and examine themes from the interview data in a systematic, efficient and ethical way that would facilitate transparency of the methods and procedures used (Guest et al., 2012). ATA would also support the demonstration of methodological and analytic rigour for a VIVA.
The aforementioned research question is suitable for this form of analysis, as well as the proposed sampling and data collection methods. A sample size of 8 participants is an acceptable sample size for ATA. Semi-structured interviews work well with ATA as they are objective collections of the participants' lived story – "words will speak for themselves..." (Starks & Trinidad, 2007). The use of probing questions and prompts will therefore be appropriate for ATA, in order to encourage the participants to elaborate when necessary. Relevant literature, manuals and online resources will be accessed.
All interviews will be carried out first, and then each interview will be analysed and coded in order of the date in which they were conducted. With regards to the presentation of the findings, they may be presented diagrammatically.
The audience for this piece of research is appropriate and representative of the audiences usually aimed at by ATA – clinicians, researchers and other professionals.
The research team at NWCPP Bangor University will be available and contactable should further guidance on the qualitative analysis be required/ advised.

6. MANAGEMENT OF THE RESEARCH

A63. Other key investigators/collaborators. *Please include all grant co-applicants, protocol co-authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.*

	Title	Forename/Initials	Surname
	Dr	Kristina	Cole
Post	Chartered Clinical Psychologist		
Qualifications	DClinPsy (Doctorate of Clinical Psychology)		
Employer	Betsi Cadwaladr University Health Board		
Work Address	Roslin CMHT, Nant Y Gamar Road, Craig Y Don, Llandudno, Conwy		
Post Code	LL30 1YE		
Telephone	01492 860926		
Fax			
Mobile			
Work Email	kristina.cole@wales.nhs.uk		

	Title	Forename/Initials	Surname
	Miss	Tania	Heath
Post	ASD Development Worker		
Qualifications			
Employer	Conwy & Denbighshire County Council		

Work Address	Government Buildings Dinerth Road Colwyn Bay
Post Code	LL28 4UL
Telephone	
Fax	
Mobile	07767002911
Work Email	tania.heath@conwy.gov.uk

A64. Details of research sponsor(s)

A64-1. Sponsor

Lead Sponsor

Status:
- ◯ NHS or HSC care organisation
- ◉ Academic
- ◯ Pharmaceutical industry
- ◯ Medical device industry
- ◯ Local Authority
- ◯ Other social care provider (including voluntary sector or private organisation)
- ◯ Other

Commercial status: Non-Commercial

If Other, please specify:

Contact person

Name of organisation	Bangor University School of Psychology
Given name	Hefin
Family name	Francis
Address	School of Psychology
Town/city	Bangor
Post code	LL7 2AS
Country	UNITED KINGDOM
Telephone	01248388339
Fax	
E-mail	H.Francis@bangor.ac.uk

Is the sponsor based outside the UK?

◯ Yes ◉ No

Under the Research Governance Framework for Health and Social Care, a sponsor outside the UK must appoint a legal representative established in the UK. Please consult the guidance notes.

Full Set of Project Data IRAS Version 5.3.0

A65. Has external funding for the research been secured?

- ☐ Funding secured from one or more funders
- ☐ External funding application to one or more funders in progress
- ☑ No application for external funding will be made

What type of research project is this?

- ◉ Standalone project
- ○ Project that is part of a programme grant
- ○ Project that is part of a Centre grant
- ○ Project that is part of a fellowship/ personal award/ research training award
- ○ Other

Other – please state:

A66. Has responsibility for any specific research activities or procedures been delegated to a subcontractor (other than a co-sponsor listed in A64-1) ? *Please give details of subcontractors if applicable.*

○ Yes ◉ No

A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?

○ Yes ◉ No

Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.

A68-1. Give details of the lead NHS R&D contact for this research:

	Title	Forename/Initials	Surname
	Dr	Rossela	Roberts
Organisation	Betsi Cadwaladr University Health Board		
Address	Research & Development		
	Ysbyty Gwynedd Hospital,		
	Bangor, Gwynedd.		
Post Code	LL57 2PW		
Work Email	rossela.roberts@wales.nhs.uk		
Telephone	01248384877		
Fax			
Mobile			

Details can be obtained from the NHS R&D Forum website: http://www.rdforum.nhs.uk

A69-1. How long do you expect the study to last in the UK?

Planned start date: 01/07/2015
Planned end date: 31/07/2016

Full Set of Project Data IRAS Version 5.3.0

Total duration:

Years: 1 Months: 0 Days: 31

A71-1. Is this study?

○ Single centre
◉ Multicentre

A71-2. Where will the research take place? *(Tick as appropriate)*

☐ England
☐ Scotland
☑ Wales
☐ Northern Ireland
☐ Other countries in European Economic Area

Total UK sites in study 2

Does this trial involve countries outside the EU?

○ Yes ◉ No

A72. Which organisations in the UK will host the research? *Please indicate the type of organisation by ticking the box and give approximate numbers if known:*

☐ NHS organisations in England	
☑ NHS organisations in Wales	1
☐ NHS organisations in Scotland	
☐ HSC organisations in Northern Ireland	
☐ GP practices in England	
☐ GP practices in Wales	
☐ GP practices in Scotland	
☐ GP practices in Northern Ireland	
☐ Joint health and social care agencies (eg community mental health teams)	
☐ Local authorities	
☐ Phase 1 trial units	
☐ Prison establishments	
☐ Probation areas	
☐ Independent (private or voluntary sector) organisations	
☑ Educational establishments	1
☐ Independent research units	
☐ Other (give details)	

Total UK sites in study: 2

A73-1. Will potential participants be identified through any organisations other than the research sites listed above?

○ Yes ◉ No

A74. What arrangements are in place for monitoring and auditing the conduct of the research?

The research will be monitored and audited by both the research supervisor Dr Kristina Cole but also the North Wales Clinical Psychology Programme (NWCPP) at Bangor University, which as part of the researcher's DClinPsy training requirements will involve the research team and the researcher's training coordinator liaising with the researcher and the research supervisor on a regular basis to assess the conduct of the researcher. The researcher will also be required to write and submit detailed research progress reports to the NWCPP research team to demonstrate their progress and their professional conduct.

A76. Insurance/ indemnity to meet potential legal liabilities

***Note:** in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland*

A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research? *Please tick box(es) as applicable.*

Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.

☐ NHS indemnity scheme will apply (NHS sponsors only)

☑ Other insurance or indemnity arrangements will apply (give details below)

Bangor University will meet the potential legal liability of the sponsor for harm to participants arising from the management of the research.
Please see attached sponsorship let ter.

Please enclose a copy of relevant documents.

A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research? *Please tick box(es) as applicable.*

Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.

☐ NHS indemnity scheme will apply (protocol authors with NHS contracts only)

☑ Other insurance or indemnity arrangements will apply (give details below)

Bangor University will meet the potential legal liability of the sponsor for harm to participants arising from the management of the research. Please see attached sponsorship letter.

Please enclose a copy of relevant documents.

A76-3. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the conduct of the research?

Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.

Full Set of Project Data IRAS Version 5.3.0

☑ NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)

☐ Research includes non-NHS sites (give details of insurance/ indemnity arrangements for these sites below)

NHS Indemnity scheme applies as participants will be NHS patients .

Please enclose a copy of relevant documents.

A78. Could the research lead to the development of a new product/process or the generation of intellectual property?

◯ Yes ◉ No ◯ Not sure

PART C: Overview of research sites

Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites. *For NHS sites, the host organisation is the Trust or Health Board. Where the research site is a primary care site, e.g. GP practice, please insert the host organisation (PCT or Health Board) in the Institution row and insert the research site (e.g. GP practice) in the Department row.*

Research site		Investigator/ Collaborator/ Contact	
Institution name	Betsi Cadwaladr University Health Board	Title	Dr
Department name	Roslin CMHT	First name/ Initials	Kristina
Street address	Nant Y Gamar Road, Craig Y Don	Surname	Cole
Town/city	Llandudno		
Post Code	LL30 1YE		
Institution name	Bangor University	Title	Dr
Department name	NWCPP, Department of Psychology	First name/ Initials	Robert
Street address	43 College Road	Surname	Jones
Town/city	Bangor		
Post Code	LL57 2DG		

Appendix G: North Wales Research Ethics Committee: Acknowledgement of Amendments & Favourable Opinion

Pwyllgor Moeseg Ymchwil Cymru 5
Wales Research Ethics Committee 5
Bangor

Clinical Academic Office
Ysbyty Gwynedd Hospital
Betsi Cadwaladr University Health Board
Bangor, Gwynedd
LL57 2PW

Telephone/ Facsimile: 01248 - 384.877
Email: Rossela.Roberts@wales.nhs.uk
Website : www.nres.nhs.uk

Mrs Aimee Jane Hooper
Trainee Clinical Psychologist
NWCPP, School of Psychology,
Brigantia Building, Bangor University,
Bangor, Gwynedd
LL57 2DG psp2ce@bangor.ac.uk

30 April 2015

Dear Mrs Hooper,

Study title:	**A qualitative study looking at the strategies that adult higher functioning women on the autistic spectrum report in order to compensate for and 'mask' social skills deficits.**
REC reference:	**15/WA/0142**
IRAS project ID:	**169142**

Thank you for your letter of 24 April 2015, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager, Dr Rossela Roberts, rossela.roberts@wales.nhs.uk. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Covering letter on headed paper [Response to Ethics Committee]	1	24 April 2015
REC Application Form [REC_Form_30042015]		30 April 2015
Research protocol or project proposal [LSRP Proposal]	2	24 April 2015
Participant information sheet (PIS) [Information Sheet]	2	24 April 2015
Participant consent form [Consent Form]	2	24 April 2015
Interview schedules or topic guides for participants [Interview Questions]	2	24 April 2015
Summary CV for Chief Investigator [Mrs Aimee Jane Hooper]	-	-
Summary CV for supervisor (student research) [Dr Kristina Cole]	-	-
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [UMAL]		01 August 2014

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

15/WA/0142	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely

Rossela Roberts

Mr Derek James Crawford, MBChB, FRCS
Chair
E-mail: rossela.roberts@wales.nhs.uk

Enclosure: "After ethical review – guidance for researchers"

SL-AR2 After ethical review - research oth

Copy:

Sponsor:
Mr Hefin Francis
School of Psychology,
Bangor University,
Brigantia Building,
Penrallt Road,
Bangor, Gwynedd, LL57 2AS
h.francis@bangor.ac.uk

Academic Supervisor:
Dr Kristina Cole
Roslin CMHT
Nant y Gamar Rd
Craig y Don, Llandudno, LL30 1YE
kristina.cole@wales.nhs.uk

R&D Office:
Dr Nefyn Williams
c/o: Miss Debra Slater
Clinical Academic Office
Ysbyty Gwynedd Hospital
Betsi Cadwaladr University Health Board
Bangor, Gwynedd, LL57 2PW
debra.slater@wales.nhs.uk

Appendix H: Research & Development Approval

GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol Betsi Cadwaladr University Health Board

Panel Arolygu Mewnol Y&D - Canolog
R&D Internal Review Panel

Betsi Cadwaladr University Health Board
Ysbyty Gwynedd
Clinical Academic Office
Bangor, Gwynedd
LL57 2PW

Chairman/Cadeirydd – Dr Nefyn Williams PhD, FRCGP
Email: rossela.roberts@wales.nhs.uk
debra.slater@wales.nhs.uk
sion.lewis@wales.nhs.uk
Tel/Fax: 01248 384 877

Mrs Aimee Hooper
Trainee Clinical Psychologist
North Wales Clinical Psychology Programme
School of Psychology, Brigantia Building,
Bangor University,
Bangor,
Gwynedd
LL57 2DG psp2ce@bangor.ac.uk

16th June 2015

Dear Mrs Aimee Hooper

Re: Confirmation that R&D governance checks are complete / R&D approval granted

Study Title	**Investigating Social Skills in female autism**
IRAS reference	169142
REC reference	15/WA/0142

The above research project was reviewed at the meeting of the BCUHB R&D Internal Review Panel

The Panel is satisfied with the scientific validity of the project, the risk assessment, the review of the NHS cost and resource implications and all other research management issues pertaining to the application.

The Internal Review Panel is pleased to confirm that all governance checks are now complete and to grant approval to proceed at Betsi Cadwaladr University Health Board sites as described in the application.

The documents reviewed and approved are listed below:

Document:	Version	Date
R&D Form	V4.0.0	30/04/2015
SSI Form	V4.0.0	29/04/2015
Protocol	V2	24/04/2015
Participant Information Sheet	V2	24/04/2015
Consent Form	V2	24/04/2015
Interview Schedule of questions	V2	24/04/2015
Summary CV: Hooper		Undated
Summary CV: Cole		Undated
Evidence of Insurance (UMAL)		Expires 31/07/2015
REC Favourable Opinion letter		30/04/2015
Risk Assessment		30/04/2015

All research conducted at the Betsi Cadwaladr University Health Board sites must comply with the Research Governance Framework for Health and Social Care in Wales (2009). An electronic link to this document is provided on the BCUHB R&D WebPages. Alternatively, you may obtain a paper copy of this document via the R&D Office.

Attached you will find a set of approval conditions outlining your responsibilities during the course of this research. Failure to comply with the approval conditions will result in the withdrawal of the approval to conduct this research in the Betsi Cadwaladr University Health Board.

If your study is adopted onto the NISCHR Clinical Research Portfolio (CRP), it will be a condition of this NHS research permission, that the Chief Investigator will be required to regularly upload recruitment data onto the portfolio database. To apply for adoption onto the NISCHR CRP, please go to: http://www.wales.nhs.uk/sites3/page.cfm?orgid=580&pid=31979. Once adopted, NISCHR CRP studies may be eligible for additional support through the NISCHR Clinical Research Centre. Further information can be found at:http://www.wales.nhs.uk/sites3/page.cfm?orgid=580&pid=28571 and/or from your NHS R&D office colleagues.

To upload recruitment data, please follow this link:
http://www.crncc.nihr.ac.uk/about_us/processes/portfolio/p_recruitment.
Uploading recruitment data will enable NISCHR to monitor research activity within NHS organizations, leading to NHS R&D allocations which are activity driven. Uploading of recruitment data will be monitored by your colleagues in the R&D office. If you need any support in uploading this data, please contact debra.slater@wales.nhs.uk or sion.lewis@wales.nhs.uk

If you would like further information on any other points covered by this letter please do not hesitate to contact me.

On behalf of the Panel, may I take this opportunity to wish you every success with your research.

Yours sincerely,

Dr Nefyn Williams PhD, FRCGP
Director of R&D
Chairman Internal Review Panel

Copy to:

Sponsor:	Mr Hefin Francis School of Psychology Bangor University, Bangor, Gwynedd LL57 2AS	h.francis@bangor.ac.uk
Academic Supervisor:	Dr Kristina Cole Roslin CMHT, Nant y Gamar Road Craig y Don, Llandudno, Conwy LL30 1YE	kristina.cole@wales.nhs.uk

Appendix I: Substantial Amendment to IRAS Form

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please complete the questions in order. If you change the response to a question, please select 'Save' and review all the questions as your change may have affected subsequent questions.

Please enter a short title for this project (maximum 70 characters)
Investigating social skills in female Autism 1

1. Is your project research?

(●) Yes ( ) No

2. Select one category from the list below:

( ) Clinical trial of an investigational medicinal product
( ) Clinical investigation or other study of a medical device
( ) Combined trial of an investigational medicinal product and an investigational medical device
( ) Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice
( ) Basic science study involving procedures with human participants
( ) Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology
(●) Study involving qualitative methods only
( ) Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)
( ) Study limited to working with data (specific project only)
( ) Research tissue bank
( ) Research database

If your work does not fit any of these categories, select the option below:

( ) Other study

2a. Please answer the following question(s):

a) Does the study involve the use of any ionising radiation?	( ) Yes	(●) No
b) Will you be taking new human tissue samples (or other human biological samples)?	( ) Yes	(●) No
c) Will you be using existing human tissue samples (or other human biological samples)?	( ) Yes	(●) No

3. In which countries of the UK will the research sites be located? *(Tick all that apply)*

[ ] England
[ ] Scotland
[x] Wales
[ ] Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

- ○ England
- ○ Scotland
- ◉ Wales
- ○ Northern Ireland
- ○ This study does not involve the NHS

4. Which review bodies are you applying to?

- ☑ NHS/HSC Research and Development offices
- ☐ Social Care Research Ethics Committee
- ☑ Research Ethics Committee
- ☐ Confidentiality Advisory Group (CAG)
- ☐ National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D offices, the CI must create Site-Specific Information Forms for each site, in addition to the study-wide forms, and transfer them to the PIs or local collaborators.

5. Will any research sites in this study be NHS organisations?

◉ Yes ○ No

6. Do you plan to include any participants who are children?

○ Yes ◉ No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

○ Yes ◉ No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the Confidentiality Advisory Group to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

○ Yes ◉ No

9. Is the study or any part of it being undertaken as an educational project?

◉ Yes ○ No

Please describe briefly the involvement of the student(s):
The student is a trainee Clinical Psychologist who is conducting the research (interviews with the participants and qualitative analysis of the interview content) for her third year research project/thesis in order to qualify as a clinical psychologist.

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

◉ Yes ○ No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

○ Yes ◉ No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

○ Yes ◉ No

NOTICE OF SUBSTANTIAL AMENDMENT

Please use this form to notify the main REC of substantial amendments to all research other than clinical trials of investigational medicinal products (CTIMPs).
The form should be completed by the Chief Investigator using language comprehensible to a lay person.

Details of Chief Investigator:

	Title Forename/Initials Surname
	Mrs Aimee Jane Hooper
Work Address	School of Psychology, Brigantia Building,
	Bangor University, Bangor, Gwynedd
	North Wales
PostCode	LL57 2DG
Email	psp2ce@bangor.ac.uk
Telephone	01248 388365
Fax	

Full title of study:	A qualitative study looking at the strategies that adult high functioning women on the autistic spectrum report in order to compensate for and 'mask' social skills difficulties.
Lead sponsor:	Bangor University School of Psychology
Name of REC:	Wales REC 5
REC reference number:	15/WA/0142
Name of lead R&D office:	Betsi Cadwaladr University Health Board
Date study commenced:	
Protocol reference (if applicable), current version and date:	
Amendment number and date:	

Type of amendment

(a) Amendment to information previously given in IRAS

◉ Yes ○ No

If yes, please refer to relevant sections of IRAS in the "summary of changes" below.

(b) Amendment to the protocol

○ Yes ○ No

If yes, please submit either the revised protocol with a new version number and date, highlighting changes in bold, or a document listing the changes and giving both the previous and revised text.

(c) Amendment to the information sheet(s) and consent form(s) for participants, or to any other supporting documentation for the study

(●) Yes ( ) No

If yes, please submit all revised documents with new version numbers and dates, highlighting new text in bold.

Is this a modified version of an amendment previously notified and not approved?

( ) Yes (●) No

Summary of changes

Briefly summarise the main changes proposed in this amendment. Explain the purpose of the changes and their significance for the study.
If this is a modified amendment, please explain how the modifications address the concerns raised previously by the ethics committee.
If the amendment significantly alters the research design or methodology, or could otherwise affect the scientific value of the study, supporting scientific information should be given (or enclosed separately). Indicate whether or not additional scientific critique has been obtained.

Enclosed in the checklist section of this application under 'other documents' are two documents, which are named 'Letter 1' and 'Letter 2'. They are letters which clinicians may wish to use to contact potential participants on my behalf to see if they would like to know more information and potentially take part in the study.

The initial IRAS form stated that clinicians would contact potential participants on my behalf by telephone or by face-to-face. However, some clinicians have now asked whether they could write to the participants instead - hence this substantial amendment and the enclosed letters which would be sent by the requesting clinicians.

I have written the letters myself to ensure they are ethical and appropriate and to ensure that the same letter would be consistently used for all individuals who are written to by the clinician.

As explained in the footer of the enclosed letters/documents, Letter 1 is the initial letter that the clinician would send explaining that they would like to let the individual know about the study in the instance this is something they may be interested in, and stating that they would like to send them an information pack in the post in due course that they could read should they so wish.

Letter 2 is the letter that would be enclosed within the information pack, to remind the individuals who has sent this to them and why this was.

Any other relevant information

Applicants may indicate any specific issues relating to the amendment, on which the opinion of a reviewing body is sought.

List of enclosed documents

Document	*Version*	*Date*
Letter 1	1	03/07/2015
Letter 2	1	03/07/2015

Declaration by Chief Investigator

1. *I confirm that the information in this form is accurate to the best of my knowledge and I take full responsibility for it.*
2. *I consider that it would be reasonable for the proposed amendment to be implemented.*

This section was signed electronically by Mrs Aimee Hooper on 03/07/2015 12:23.

Job Title/Post:	Trainee Clinical Psychologist
Organisation:	Betsi Cadwaladr University Health Board
Email:	psp2ce@bangor.ac.uk

Declaration by the sponsor's representative

I confirm the sponsor's support for this substantial amendment.

This section was signed electronically by Mr Hefin Francis on 06/07/2015 09:10.

Job Title/Post:	School Manager for Psychology
Organisation:	Bangor University
Email:	h.francis@bangor.ac.uk

Appendix J: North Wales Research Ethics Committee: Acknowledgement of Amendment Request & Favourable Opinion

NISCHR
Gwasanaeth Moeseg Ymchwil | RES | Research Ethics Service

Pwyllgor Moeseg Ymchwil Cymru 5
Wales Research Ethics Committee 5
Bangor

Clinical Academic Office
Ysbyty Gwynedd Hospita
Betsi Cadwaladr University Health Boarc
Bangor, Gwynedc
LL57 2PW

Telephone/ Facsimile: 01248 - 384.877
Email: Rossela.Roberts@wales.nhs.uk
Website : www.nres.nhs.uk

Mrs Aimee Jane Hooper
Trainee Clinical Psychologist
NWCPP, School of Psychology,
Brigantia Building, Bangor University,
Bangor, Gwynedd
LL57 2DG psp2ce@bangor.ac.uk

07 July 2015

Dear Mrs Hooper,

Study title:	**A qualitative study looking at the strategies that adult higher functioning women on the autistic spectrum report in order to compensate for and 'mask' social skills deficits.**
REC reference:	**15/WA/0142**
Amendment number:	**1**
Amendment date:	**03 July 2015**
IRAS project ID:	**169142**

The above amendment was reviewed at the meeting of the Sub-Committee held on 07 July 2015.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Letters of invitation to participant [Letter 1]	1	03 July 2015
Letters of invitation to participant [Letter 2]	1	03 July 2015
Notice of Substantial Amendment (non-CTIMP)	1	03 July 2015

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet. No declarations of interest were made in relation to this application.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

15/WA/0142	**Please quote this number on all correspondence**

Yours sincerely

Dr Philip Wayman White, MBChB, FRCGP
Chair
E-mail: rossela.roberts@wales.nhs.uk

Copy:

Sponsor:
Mr Hefin Francis
School of Psychology,
Bangor University,
Brigantia Building,
Penrallt Road,
Bangor, Gwynedd, LL57 2AS
h.francis@bangor.ac.uk

Academic Supervisor:
Dr Kristina Cole
Roslin CMHT
Nant y Gamar Rd
Craig y Don, Llandudno, LL30 1YE
kristina.cole@wales.nhs.uk

R&D Office:
Dr Nefyn Williams
c/o: Miss Debra Slater
Clinical Academic Office
Ysbyty Gwynedd Hospital
Betsi Cadwaladr University Health Board
Bangor, Gwynedd, LL57 2PW
debra.slater@wales.nhs.uk

North West Wales Research Ethics Committee

Attendance at Sub-Committee meeting on 07 July 2015

Committee Members

Name	*Profession*	*Capacity*	*Present*
Dr Philip W White	General Practitioner (Chairman)	Expert	Yes
Dr Jason D Walker	Consultant Anaesthetist (Vice-Chairman)	Expert	Yes

In attendance

Name	*Position (or reason for attending)*
Dr Rossela Roberts	Clinical Governance Officer / RES Manager

Appendix K: Research & Development Acknowledgement of Amendment Request

Dear Aimee,

RE: Receipt of Amendment

IRAS Ref:	169142
Short Study Title:	Investigating social skills in female Autism 1
Date received by Permissions Service:	24 Mar 2016
Amendment type:	Substantial
Amendment No./ Sponsor Ref:	Participant Letter
Amendment Date:	03 Jul 2015
UK Amendment Category:	A
35-calendar day implementation date:	28 Apr 2016
REC favourable opinion for the amendment:	Not received
MHRA Notice of Acceptance of the amendment:	Not applicable

Thank you for submitting the above amendment. This has been categorized as UK amendment category A, which ALL participating NHS organisations are expected to consider.

Please find attached a list of the documents we have received.

Those NHS organisations affected by this amendment will consider the amendment based on the information provided in this valid application.

Please send copies of the regulatory approvals for this amendment (REC) to research-permissions@wales.nhs.uk once you have received them. The Permissions Service will make these available to all participating sites.

Subject to the following conditions, you will be able to implement the amendment on the above 35-calendar day implementation date, at all NHS organisations in the UK where NHS Permission is granted:

- You may not implement this amendment at any NHS organisation that is unable to support the amendment and raises an objection to the amendment.
- You may not implement this amendment at any NHS organisation, until and unless you receive all regulatory approvals and submit them to your lead nation co-ordinating centre.
- You may not implement this amendment at any site which informs you that they require additional review time, until they notify you that this review has been satisfactorily completed.

If you receive regulatory approvals after the implementation date, you should submit them as outlined above along with any additional documents. You may then implement the amendment at NHS organisations that have already granted NHS permission and have not raised an objection to the amendment or requested additional review time.

Please note you may only implement the changes described in the valid Notice of Amendment.

As it is the responsibility of the NHS organisation to notify you that you cannot implement the amendment, you are not required to wait for the receipt of a notification of continued

permission from an NHS organisation to implement the amendment on the implementation date.

It remains the Sponsor's responsibility to supply Principal Investigators at NHS organisations with the details of the Notice of Amendment and any updated documents.

Please contact us if you require any further information. Additional information on the management of amendments, including a leaflet on the new UK process for amendments, can be found at http://www.hra.nhs.uk/nhshsc-rd-uk-process-management-amendments/ .

Kind regards,

Fiona

Research Permissions Service – Amendments Team

Email: Research-permissions@wales.nhs.uk

Health and Care Research Wales Support Centre / Canolfan Gymorth Ymchwil Iechyd a Gofal Cymru

Tel / Ffôn: 02920 230457

Website / Gwefan: gov.wales/healthandcareresearch / llyw.cymru/ymchwiliechydagofal

Twitter: @ResearchWales / @YmchwilCymru

For NHS research permission applications, amendments and related correspondence, email us here: Research-permissions@wales.nhs.uk.

Please note our email address has changed, could you please update your contact lists.

Appendix L: Research & Development Approval of Amendment

Dear Mrs Hooper,

Re: Substantial Amendment AM Participant Letters dated 03 July 2015

Study Title	Investigating Social Skills in Female Autism
R&D reference	169142
Category	A

The above amendment was reviewed by the R&D Office on the 29 March 2016 on behalf of the Internal Review Panel.

Documents reviewed:	Version	Date
Notice of Amendment Form	-	03/07/2015
Letter 1 – Invitation Letter	1	03/07/2015
Letter 2 – Participant Cover Letter	1	03/07/2015

The R&D Office have no objection and is able to support the amendment based on the information provided. The amendment does not affect local management approval previously given to this research and is approved to continue at Betsi Cadwaladr University Health Board (BCUHB) sites as described in the application.

As part of the regular monitoring undertaken by the Internal Review Panel you will be required to complete a short progress report. This will be requested on a 6 monthly basis. However, please contact me sooner should you need to report any particular successes or problems concerning your research. Whilst BCUHB is keen to reduce the burden of paperwork for researchers failure to produce a report may result in withdrawal of approval.

All research conducted at the BCUHB sites must comply with the Research Governance Framework for Health and Social Care in Wales (August 2009). An electronic link to this document is provided on the BCUHB R&D WebPages. Alternatively, you may obtain a paper copy of this document via the R&D Office.

The decision is sent to you in electronic format only – please let me know whether you will be requiring a formal letter.

On behalf of BCUHB, we would like to wish you every success with your research.

Yours sincerely

Best wishes

Mr Sion Lewis

Mr Sion Lewis

Cynorthwyydd Ymchwil a Datblygu

Research & Development Assistant

Ymchwil a Datblygu

Research and Development

Bwrdd Iechyd Prifysgol

Betsi Cadwaladr

University Health Board

Ysbyty Gwynedd Hospital

Bangor

Gwynedd

LL57 2PW

Tel: (01248) 384877 - Ext: 4877

Email: Sion.Lewis@wales.nhs.uk

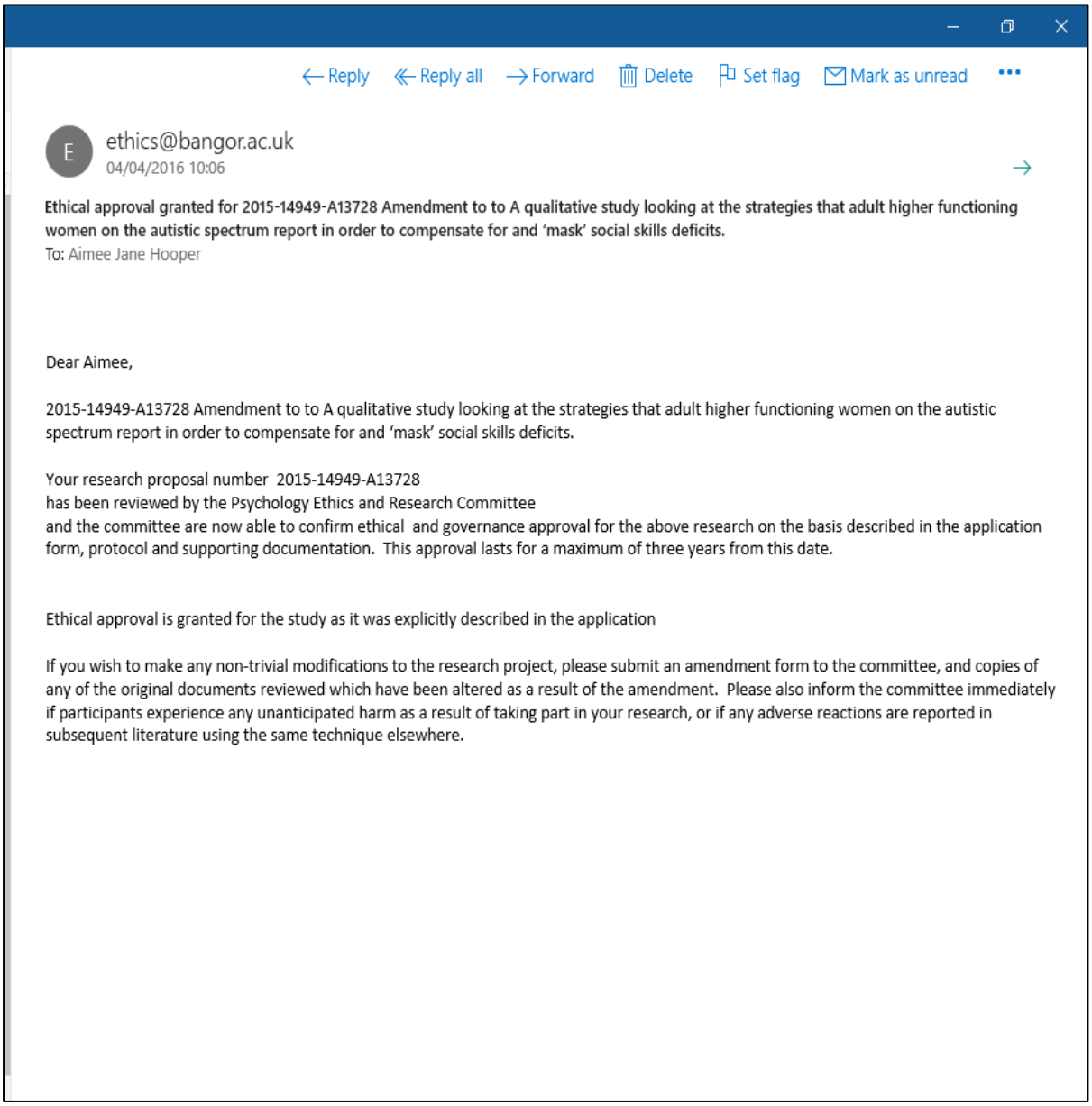
Bwrdd Iechyd Prifysgol Betsi Cadwaladr yw enw gweithredol Bwrdd Iechyd Lleol Prifysgol Betsi Cadwaladr

Betsi Cadwaladr University Health Board is the operational name of Betsi Cadwaladr University Local Health Board

Medics North Wales - http://www.wales.nhs.uk/sitesplus/1002/page/82860

Medics North Wales Twitter - @MedicsNWales

Appendix M: School Of Psychology Ethical Approval of Amendment



← Reply ≪ Reply all → Forward Delete Set flag Mark as unread •••

E ethics@bangor.ac.uk
04/04/2016 10:06 →

Ethical approval granted for 2015-14949-A13728 Amendment to to A qualitative study looking at the strategies that adult higher functioning women on the autistic spectrum report in order to compensate for and 'mask' social skills deficits.
To: Aimee Jane Hooper

Dear Aimee,

2015-14949-A13728 Amendment to to A qualitative study looking at the strategies that adult higher functioning women on the autistic spectrum report in order to compensate for and 'mask' social skills deficits.

Your research proposal number 2015-14949-A13728
has been reviewed by the Psychology Ethics and Research Committee
and the committee are now able to confirm ethical and governance approval for the above research on the basis described in the application form, protocol and supporting documentation. This approval lasts for a maximum of three years from this date.

Ethical approval is granted for the study as it was explicitly described in the application

If you wish to make any non-trivial modifications to the research project, please submit an amendment form to the committee, and copies of any of the original documents reviewed which have been altered as a result of the amendment. Please also inform the committee immediately if participants experience any unanticipated harm as a result of taking part in your research, or if any adverse reactions are reported in subsequent literature using the same technique elsewhere.

Appendix N: Participant Letter 1

Version 1
03/07/2015

Address of Clinician's Base

XXXXXXXXXXXXXXXXXXXX

XXXXXXXXXXXXXXXXXXXX

Date: XX/XX/2015

Individual's Address

XXXXXXXXXXXXXX

Dear XXXXX,

I hope you are keeping well.

I am writing today to let you know about an upcoming research study that is being conducted through Bangor University by a Trainee Clinical Psychologist called Aimee Hooper.

I wondered whether this may be something you may be interested in hearing about.

Aimee would like to carry out informal individual interviews with a small group of women with a diagnosis of Autistic Spectrum Disorder who would like an opportunity to talk about their life experiences linked to social interaction and social skills.

In case this is something you may be interested in knowing more about or want to volunteer to take part in, I would like to send you an information pack in the post next week for you to browse should you wish to.

Thank you for your time.

Yours Sincerely,

(signature XXX)

Clinician Name XXXXXXXXXXX

XXXXXXX **Clinical Psychologist**

Appendix O: Participant Letter 2

Version 1
03/07/2015

Address of Clinician's Base

XXXXXXXXXXXXXXXXXXXX

XXXXXXXXXXXXXXXXXXXX

Date: XX/XX/2015

Individual's Address

XXXXXXXXXXXXXX

Dear XXXXX,

As mentioned in my previous letter to you dated XX/XX/XXXX, I enclose an information pack about an upcoming study being conducted by Trainee Clinical Psychologist Aimee Hooper through Bangor University.

The enclosed information pack contains information about this study in both the English and Welsh language, and a freepost return envelope. The information in the pack is for you to browse should you so wish.

At the back of the participant information sheet is a return slip, which you can return to Aimee Hooper in the freepost envelope provided, should you wish to volunteer to take part in her study.

Thank you for your time.

Yours Sincerely,

(signature XXX)

Clinician Name XXXXXXXXXXX

XXXXXXX **Clinical Psychologist**

Note for Examiners: 'Letter 2' is the letter that would be enclosed within the information pack, to remind the individuals who has sent this to them and why this was.

Appendix P: Participant Information Pack (Cymraeg & English)

Version 2

24/04/2015

Taflen Wybodaeth

Project:

'Deall sgiliau cymdeithasol mewn merched ag awtistiaeth'

Enw'r Ymchwilydd: : Aimee Hooper

Gwahoddiad
Rydym yn gofyn a fyddech yn hoffi cyfrannu at astudiaeth sy'n ceisio darganfod pa strategaethau a thechnegau y mae merched ag awtistiaeth yn eu defnyddio er mwyn ymdopi mewn sefyllfaoedd cymdeithasol. Yn ogystal â chlywed pa strategaethau mae merched yn eu defnyddio, hoffem ddysgu mwy am ba bryd, a pham, gallai merched fod yn gwneud hyn.

Cyn i chi benderfynu a ydych am gymryd rhan, hoffem egluro pam mae'r astudiaeth yn cael ei chynnal, a phe baech yn cymryd rhan, beth fyddai'n digwydd. Darllenwch y wybodaeth, os gwelwch yn dda, a meddyliwch amdani'n ofalus. Mynnwch sgwrs gyda'ch teulu neu'ch ffrindiau am yr astudiaeth os ydych yn dymuno.

Beth yw pwrpas yr astudiaeth?
Ein gobaith yw y bydd yr ymchwil yn gwella ein dealltwriaeth o sut mae merched yn ymdopi â'r anawsterau cymdeithasol sy'n gysylltiedig ag awtistiaeth a sut y gallai hyn effeithio ar y diagnosis o awtistiaeth mewn merched.

Pwy sy'n cynnal yr ymchwil?
Mae'r astudiaeth yn cael ei chynnal fel rhan o hyfforddiant Aimee Hooper i fod yn seicolegydd clinigol. Aelodau eraill y tîm ymchwil yw'r goruchwyliwr academaidd **Dr Kristina Cole** sy'n Seicolegydd Clinigol Siartredig yn gweithio yn Nhîm Iechyd Meddwl Cymunedol Roslin yn Llandudno, a Chydweithiwr Ymchwil **Tania Heath** sydd yn weithiwr datblygu ASD gyda Chyngor Sirol Conwy

Pam rydw i wedi cael gwahoddiad i gymryd rhan?
Rydym wedi gofyn i chi a hoffech chi gymryd rhan oherwydd ein bod yn gwahodd grŵp bychan o ferched rhwng 19-60 oed sydd ag awtistiaeth i gael cyfweliad unigol.

Oes rhaid imi gymryd rhan?
Mae pobl yn cymryd rhan o'u gwirfodd felly chi sydd i benderfynu a ydych chi am gymryd rhan ai peidio. . Os cytunwch i gyfweliad, byddwn yn gofyn ichi lofnodi a dychwelyd y bonyn isod. Rydych yn rhydd i dynnu'n ôl o'r astudiaeth unrhyw bryd,

heb fod angen i chi roi rheswm, ac ni fydd hyn yn effeithio ar eich triniaeth na'ch hawliau cyfreithiol.

Beth fydd yn digwydd i mi os byddaf yn cymryd rhan?
Os penderfynwch gymryd rhan yn yr astudiaeth, hyn fydd yn digwydd**:**

- Byddwch yn cael gwahoddiad i gyfweliad (trafodaeth) gyda'r ymchwilydd Aimee Hooper ar ddyddiad ac amser a gytunir ac sy'n gyfleus i chi. Bydd y cyfweliad yn cael ei gynnal naill ai ym Mhrifysgol Bangor neu yn swyddfeydd Tîm Iechyd Meddwl Cymunedol Roslin. Bydd yn dibynnu ar beth sydd fwyaf cyfleus i chi. Gallwch ddod â ffrind, partner neu weithiwr proffesiynol cefnogol i'r cyfweliad gyda chi i'ch cefnogi os dymunwch. Byddwn yn gofyn iddynt aros yn yr ystafell aros tra bydd y cyfweliad yn cael ei gynnal.

- Ar ddiwrnod y cyfweliad bydd Aimee yn mynd trwy'r ffurflen gydsynio ffurfiol gyda chi, yn ateb unrhyw gwestiynau sydd gennych, ac yn gofyn i chi lofnodi'r ffurflen hon os ydych yn dal i fod yn fodlon cymryd rhan.

- Caiff y cyfweliad ei gynnal yn Saesneg , a bydd yn para tua **60 munud**. Gallwch gymryd seibiant, stopio neu wrthod ateb unrhyw gwestiynau pe baech chi am wneud hynny. Yn ystod y cyfweliad bydd Aimee Hooper yn gofyn rhai cwestiynau i chi nad oes atebion cywir nac anghywir iddynt - y cyfan fydd ei angen fydd i chi ddweud eich hanes a rhoi eich barn. **Bydd lluniaeth ysgafn ar gael yn yr ystafell gyfweld.** Fe gewch ad-daliad o'ch costau teithio i'r cyfweliad, ar ddiwrnod y cyfweliad, hyd at swm o £18.00 .

- Bydd y sgwrs yn cael ei sain-recordio fel bod modd defnyddio cynnwys y trafodaethau ar gyfer yr astudiaeth. Gofynnir am eich caniatâd i sain-recordio'r cyfweliad cyn dechrau. Caiff yr holl recordiadau eu cadw'n ddiogel ar gof bach dan gyfrinair. Dim ond Aimee fydd yn gwybod y cyfrinair. Caiff y cof bach ei gadw'n ddiogel mewn swyddfa dan glo ym mwrdd iechyd y brifysgol.

- Unwaith y bydd Aimee Hooper wedi casglu canlyniadau'r astudiaeth, bydd hi'n ysgrifennu atoch, oni bai eich bod yn gofyn iddi beidio, **i roi adborth i chi ar ganfyddiadau'r astudiaeth ac i ddiolch i chi am eich cyfraniad.**

- Caiff canlyniadau'r astudiaeth eu rhoi mewn adroddiad a all gael ei gyhoeddi mewn cylchgrawn ar-lein ond ni fydd unrhyw fanylion personol yn cael eu cynnwys fel na fydd modd eich adnabod ac ni fydd unrhyw ddyfyniadau uniongyrchol o'r cyfweliadau'n cael eu hadrodd heb eich caniatâd.

Beth yw risgiau posibl cymryd rhan?
Mae rhai pobl yn cael cyfweliad ymchwil yn anodd, felly os byddwch yn ei chael hi'n anodd, bydd Aimee Hooper yn holi i weld a ydych yn iawn. Bydd hi'n cynnig cyfle i chi gael seibiant neu gyfle i siarad gyda hi neu'r unigolyn sydd wedi dod gyda chi os hoffech wneud hynny. Gallwch roi gwybod iddi os ydych yn cael anhawster ar unrhyw adeg yn ystod y cyfweliad a gofyn am seibiant neu roi'r gorau iddi'n gyfan gwbl.

Beth yw manteision posib cymryd rhan?
Gall y wybodaeth a gawn o'r astudiaeth ein helpu i ddeall merched ag awtistiaeth yn well, a rhoi gwell diagnosis a thriniaeth. Mae'n bosib y bydd y cyfweliad yn brofiad cadarnhaol i chi oherwydd bydd cyfle i chi ddweud eich stori a chael rhywun i wrando arnoch a chlywed eich barn.

A fydd fy nghyfraniad yn cael ei gadw'n gyfrinachol?
Bydd yr holl wybodaeth a gesglir amdanoch yn ystod yr ymchwil yn cael ei chadw'n hollol gyfrinachol, a dilëir eich enw a'ch cyfeiriad a chewch rif adnabod cyfrannwr, fel nad oes modd eich adnabod.
Ni fyddwn yn torri cyfrinachedd oni bai eich bod yn dweud rhywbeth sydd yn arwain Amy i bryderu'n ddifrifol am eich diogelwch chi neu rywun arall. Mewn achos felly byddai Aimee yn eich cefnogi, ac yn trafod opsiynau posib. Byddai Aimee yn rhoi gwybod i weithiwr proffesiynol perthnasol am ei phryderon. Byddai'r gweithiwr proffesiynol hwnnw'n rhoi cyngor ynghylch beth i'w wneud nesaf a phwy fyddai'r person gorau i roi cyngor pellach.

Â phwy y dylwn gysylltu i gael mwy o wybodaeth?
Os oes gennych unrhyw gwestiynau, gallwch adael neges gyda'ch rhif cyswllt gyda **Dr Kristina Cole** ar **(01492) 860926**. Bydd Dr Kristina Cole yn rhoi eich neges i Aimee Hooper cyn gynted ag y bo modd. Os nad yw Dr Cole ar gael gofynnwch i'r derbynnydd roi neges i Aimee Hooper ynghylch yr astudiaeth a bydd Aimee yn eich ffonio'n ôl cyn gynted ag y bo modd.

Os ydych chi eisiau gofyn rhagor o gwestiynau neu adael adborth am yr astudiaeth, gallwch gysylltu â:

- Rhaglen Seicoleg Glinigol Gogledd Cymru,
  Ysgol Seicoleg
  Adeilad Brigantia
  Prifysgol Bangor
  Bangor
  LL57 2DG
- Ffôn: 01248 388365

Neu

- Tîm Pryderon, Bwrdd Iechyd Prifysgol Betsi Cadwaladr, Ysbyty Gwynedd, Bangor, Gwynedd, LL57 2PW
- E-bost: ConcernsTeam.bcu@wales.nhs.uk). Ffôn: 01248 384194.

Os hoffech gwyno am yr astudiaeth hon, cysylltwch â:

- Hefin Francis, Ysgol Seicoleg, Adeilad Brigantia, Ffordd Penrallt, Gwynedd LL57 2AS, E-bost:
- Ebost: h.francis@bangor.ac.uk, Ffôn: 01248 388339.

Beth sy'n digwydd nesaf?

Os hoffech gymryd rhan, llofnodwch a dychwelwch y bonyn isod.
Diolch.

- Os gwelwch yn dda, dychwelwch y ffurflen hon, wedi ei llofnodi, yn yr amlen â stamp a ddarparwyd. **erbyn:**_____

Enw'r Cyfrannwr: _____

Llofnod y Cyfrannwr:
_____

Dyddiad:_____

- **Hoffech i ni gysylltu â chi i drefnu eich cyfweliad trwy...**

(ticiwch)

1. Llythyr ☐
(Cyfeiriad post:_____)

NEU

2. Ffôn ☐
(Rhif ffôn:_____)

Version 2
24/04/2015

Information Sheet

Project:

'Understanding social skills in female autism'

Name of Researcher: Aimee Hooper

Invitation

We are asking if you would like to contribute to a study that is looking to find out what strategies and techniques women with Autism may be using in order to cope in social situations. In addition to hearing what strategies women use, we would like to learn more about when, and why women might be doing this.

Before you decide if you would like to take part, we would like to explain why the study is being done and if you were to take part, what this would involve. Please read through and think about this information carefully. Talk to your family or friends about the study if you wish to.

What is the purpose of the study?

Our hope is that the research will improve our understanding of how women cope with the social difficulties associated with Autism and how this might effect the diagnosis of Autism in women.

Who is conducting the research?

The study is being conducted as part of **Aimee Hooper**'s training to be a Clinical Psychologist. The other members of the research team are Academic Supervisor **Dr Kristina Cole** who is a Chartered Clinical Psychologist working at Roslin Community Mental Health Team (Roslin CMHT) in Llandudno, and Research Collaborator **Tania Heath** who is an ASD Development Worker for Conwy County Council.

Why have I been invited to take part?

You have been asked if you would like to take part because we are inviting a small group of women aged 19-60 years with Autism to give an individual interview.

Do I have to take part?

Participating is entirely voluntary, so **it is up to you to decide if you would like to take part**. If you agree to be interviewed, we will ask you to sign and return the slip below. You are free to withdraw from the study at any time without needing to give a reason, and your treatment and legal rights will not be effected by this.

What will happen to me if I take part?

If you decide to take part in the study, your involvement will include the following**:**

- You will be invited on an agreed date and time that is convenient for you, to attend an **interview (discussion)** with researcher Aimee Hooper. The interview will take place at either **Bangor University or Roslin CMHT**, depending on what is more convenient for you. You **can bring a friend, partner or supportive professional** to the interview with you for support if you so wish. They will be asked to wait in the waiting room whilst the interview takes place.

- On the day of the interview Aimee will talk through the formal **consent form** with you, will answer any questions you have, and ask you to sign this form if you still agree to take part.

- The interview will be carried out in **English**, and last approximately **60 minutes**. You will be able to have a break, stop or refuse to answer any questions should you want to. During the interview Aimee Hooper will ask you some questions that will have no right or wrong answers – we would just like to hear your story and opinions. **Refreshments** will be made available in the interview room. The costs of travelling to the interview will be **reimbursed** to you on the day of interview, up to the cost of **£18.00**.

- What you discuss will be **audio recorded** so that the content of the discussions can be used for the study. You will be asked for your consent to be audio recorded before starting the interview. All recordings will be **securely stored** on a password protected USB stick that only Aimee will know the password to. This will be safely stored on secure university health board premises.

- Once the results of the study have been collected, Aimee Hooper will write to you, unless you ask her not to, to **provide you with feedback** about what was found from the study and thanking you for your contribution.

- The results from the study will written up into a report, which may be published in an online journal, but your personal details will not be identifiable and no direct quotations from the interviews will be reported without your consent.

What are the possible risks of taking part?

Some people find research interviews difficult, so if you do find it hard, Aimee Hooper will check that you are OK. She will offer you a break or the chance to stop and talk with her or your chaperone if you would like to. You can let her know if you are finding it difficult at any time during the interview and request a break or to stop completely.

What are the possible benefits of taking part?

The information we get from the study may help to increase the understanding, diagnosis and treatment of women with Autism. It is possible that you may find the interview a positive experience due to the opportunity to be listened to and have your story and opinions heard.

Will my taking part be kept confidential?

All information collected about you during the course of the research will be kept confidential, and your name and address will removed and given a participant identification number, so that you cannot be identified.

Confidentiality will only be challenged in the rare instance that you report something which leads Aimee to be seriously concerned about your own or another's safety. In this instance Aimee will support you, and discuss possible options. Aimee would inform a relevant professional of her concerns. This professional would give advice on what to do next and who to contact for further advice.

Who should I contact for further information?

If you have any questions, you can leave a message along with your contact number with **Dr Kristina Cole** on **(01492) 860926**. Dr Kristina Cole will pass on your message to Aimee Hooper as soon as possible. If Dr Cole is not available please ask the receptionist to leave a message regarding Aimee Hooper's study and Aimee will return your call as soon as possible.

If you wish to ask further questions or leave feedback about the study, you can either contact:

- North Wales Clinical Psychology Programme, School of Psychology, Brigantia Building, Bangor University, Bangor, LL57 2DG
- Tel: 01248 388365

Or

- Betsi Cadwaladr University Health Board Concerns Team, Ysbyty Gwynedd, Bangor, LL57 2PW.
- Email: ConcernsTeam.bcu@wales.nhs.uk, Tel: 01248 384194.

If you would like to make a complaint about this study, please contact:

- Hefin Francis, School of Psychology, Adeilad Brigantia, Penrallt Road, Gwynedd LL57 2AS.
- Email: h.francis@bangor.ac.uk, Tel: 01248 388339.

What Happens Next?

If you **would like to take part**, please **sign and return** the slip below.

Thank You.

- Please **return this signed form to the researcher** in the pre-paid envelope provided, **by:**_____

Participant Name: _____

Participant Signature:_____

Date:_____

- **You would like to be contacted to arrange your interview by…**

(please tick)

1. Letter
   (Postal Address:_____) ☐

OR

2. Telephone
   (Telephone Number:_____) ☐

Understanding social skills in female Autism
Ethics Approval No.:
Participant Identifier:

Appendix Q: Participant Consent Form (Cymraeg & English)

Version 2

24/04/2015

Ffurflen Gydsynio

Project:

'Deall sgiliau cymdeithasol mewn merched ag awtistiaeth'

Enw'r ymchwilydd: Aimee Hooper

Cwestiynau hanfodol:

(Rhowch lythrennau blaen eich enw ym mhob blwch)

1. Cadarnhaf fy mod wedi darllen y daflen wybodaeth dyddiedig 24/04/2015 (Fersiwn 2) mewn perthynas â'r astudiaeth uchod. Rwyf wedi cael cyfle i ystyried y wybodaeth a gofyn cwestiynau ac wedi cael atebion boddhaol iddynt. ☐

2. Rwy'n deall fy mod yn cymryd rhan o'm gwirfodd ac y gallaf dynnu'n ôl ar unrhyw adeg, heb roi rheswm a heb i hynny effeithio ar fy nhriniaeth na'm hawliau cyfreithiol. ☐

3. Rwy'n deall y bydd yr holl wybodaeth bersonol a gesglir gan yr ymchwilydd yn ystod y cyfweliad neu ar ei ôl yn cael ei chadw'n ddiogel ac yn gyfrinachol. ☐

4. Rwy'n deall bod eithriadau i hyn lle bydd yn rhaid i'r ymchwilydd efallai dorri cyfrinachedd, os byddaf yn rhoi gwybod i'r ymchwilydd y gallaf i neu eraill fod mewn perygl difrifol. ☐

5. Deallaf os byddaf yn dweud wrth yr ymchwilydd y gallaf i neu eraill fod mewn peryg difrifol, y bydd yn rhaid i'r ymchwilydd gysylltu â gweithiwr proffesiynol

perthnasol a fydd yn penderfynu beth i'w wneud nesaf ac â phwy i gysylltu er mwyn fy niogelu i ac eraill. ☐

6. Deallaf y bydd y wybodaeth a gesglir yn cael ei sain-recordio. ☐

7. Rwy'n cytuno i'm cyfweliad gael ei sain-recordio. ☐

8. Rwy'n hapus i ddyfyniadau uniongyrchol dienw o'm cyfweliad gael eu defnyddio mewn adroddiad ac efallai eu cyhoeddi. ☐

9. Cytunaf i gymryd rhan yn yr astudiaeth uchod. ☐

Os ydych chi wedi cytuno i gymryd rhan yn yr astudiaeth, ysgrifennwch eich enw a llofnodwch isod:

Enw'r Cyfrannwr: _____

Llofnod y Cyfrannwr:
_____

Dyddiad: _____

Enw'r ymchwilydd: _____

Llofnod: _____

Dyddiad: _____

DIOLCH YN FAWR

Version 2

24/04/2015

Consent Form

Project:

'Understanding social skills in female autism'

Name of Researcher: Aimee Hooper

Essential Questions: (Please initial each box)

1. I confirm that I have read the information sheet dated 24/04/2015 (Version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my treatment or legal rights being affected. ☐

3. I understand that all personal information gathered by the researcher during and after the interview will remain confidential and secure. ☐

4. I understand that there are exceptions in which the researcher may need to challenge confidentiality, if I inform the researcher that myself or others may be at serious risk. ☐

5. I understand that if I inform the researcher that myself or others may be at serious risk, that the researcher will need to contact a relevant professional who will decide what to do next and who to contact to ensure my own and others safety. ☐

6. I understand that the information collected in the interviews will be audio recorded. ☐

7. I am happy for my interview to be audio recorded. ☐

8. I am happy for anonymous direct quotations from my interview to be reported and potentially published. ☐

9. I agree to take part in the above study. ☐

If you have **agreed** to take part in the study, please **write your name and sign below**:

Name of Participant: _____

Participant Signature:_____

Date: _____

Researcher Name: _____

Signature: _____

Date: _____

THANK YOU

Understanding social skills in female Autism
Ethics Approval No.:
Participant Identifier:

Appendix R: Interview Schedule

Version 2
24/04/2015

Intro/Icebreaker: Thank you for coming today and agreeing to take part in this study. For the next hour or so I am going to be asking you some questions, but if at any point you would like to take a break or stop please just let me know at any time.

To begin with, I would like to just ask you some brief demographic questions if I may?

1. How old are you?

2. What is your nationality?

3. What is your ethnicity?

2. What is your marital status?

3. Do you have any children?

4. What is your occupation?

5. How old were you when you received your ASD diagnosis?

Questions	Probes/ Prompts
1. **How do you find social situations (being around and talking with other people)?**	Can you tell me more about that please? Have you got any **examples** of this? How is it easy/difficult? What makes it easier/ more difficult? What **situations** are manageable/ more difficult? What is it about them/it that makes it **easier/ harder**? **What type of places/ situations** did you try them in? **When** did you first start doing/ noticing this? **Where/ Who** did you learn this from? **How** did you do this? How **helpful/ successful** was that? Please can you explain that to me a bit more?
2. ***Some*** **people with autism say that they use specific strategies (do certain things) to help them in social situations. For example, being told what is the right thing to say by family or friends, etc.** ***If*** **this is something you have experienced, please could you tell me more about that?**	
3**. *Some*** **people with autism say that they have copied or mimicked someone or something else, to help them in social situations. For example, a celebrity or fictional character, etc.** ***If*** **this is something you have experienced, please could you tell me more about that?**	

Concluding Statement/ Cool Down:

Thank you very much for all of your time and effort today - your contribution is really appreciated.

Do you have any other questions for me?

Do you have anything else you would like to discuss?

Thank you very much again for coming today.

Section Six:

General Appendices

Appendix A

Familiarisation Note Excerpt

Participant 11

- One-to-one situations and interactions with people she knows well are easier as she knows how they communicate. However, this is also dependent on her mood at the time.
- New environments are difficult but enjoys meeting new people.
- Experiences shutdowns whereby she would rather not be there or is disinterested in the topic of conversation – happens both intentionally and unintentionally.
- Gets distracted by own thoughts whilst trying to pay attention in conversations.
- Reads people as much as she can in social situations (i.e. body language; facial expressions) – does not need to do it as much with people she knows very well, is more relaxed.
- Repeats things or asks a question to double check people's meanings in case she or they have misunderstood.
- Sensory sensitivity to noise makes chairing meetings difficult and unenjoyable. Will cover ears with fingers under her hair to reduce noise levels in meetings.
- People misinterpret her as being patronising if she doesn't understand what they've said and asks them to rephrase or repeat something. Husband is a bit more patient now post-diagnosis.
- Can communicate well with her husband as they have made adaptations to the way they communicate to help her understand things better (i.e. particular personal shared gestures).

- Mum told her what to say or what not to say when younger in friendships, telling her how to manage friendships, talk quieter, tell people less, etc. Mum would tell her what to say or what not to say to friends.
- Mum tells her in adulthood to speak quieter as people may find her loud voice tiresome.
- Masks her confusion or misunderstanding in social situations by re-iterating someone's meaning or repeating what they've said to double check she has understood them right without them particularly noticing she has done it.
- Does mental checks to assess whether she's talked too much in a conversation and needs to stop.
- Used to try and camouflage and blend in at school but stopped this when she left school and now prefers to be herself but makes an effort to be a nice person to people.
- Mimics other people's body language in social situations – used to be intentional but now had become more natural with practice and does not have to overthink about it as much.
- Has to remind herself of social norms and conventions to fit in socially at work (i.e. collections for a leaving present, etc.).

Appendix B

Example of Coded Transcript

Participant 11

	Transcript excerpt	Initial Codes
1	I: Thank you so much. So, my second question is that <u>some</u> people with autism say that they use	
2	specific strategies, so do certain things, to help them interact with other people. <u>If</u> this is something	
3	you've experienced please could you tell me more about that?	
4	P: (laugh) My mum tells me erm, I could tell you when I was younger my mum told me you know what	▪ Being told what to say or what not to say by mum
5	to say and what not to say, but nowadays I think she just tells me to be quieter 'cos she knows I'm loud	▪ Mum as a social guide ▪ Being told to speak quieter to be less tiresome
6	and people find that quite tiresome – not because they don't wanna listen to me, but because I get really	▪ Fluctuating awareness of own volume of speech
7	loud and they get a bit tired listening to that volume of conversation is what my mum said, and that's	▪ Worrying about social errors
8	something I've always had and sometimes I'm very aware of it and at other times I'm completely	▪ Unsure about her own behaviours
9	unaware, and I'll go '<u>oh no</u> <u>I'm sure I was too loud or too excited'</u> (whispering tone) and I'll (sigh)	▪ No longer told what to say unless too loud
10	when I'm back afterwards I'll go '<u>oh no'</u>. So that's the one thing that I guess happens now, but no one	▪ Not told what to say in adulthood
11	ever tells me what to say and what not to say anymore, apart from that (laugh). My mum says that and I	▪ No longer follows mums advice
12	don't really listen to her. I'm just like yeah I know but erm, (laugh) no I I wouldn't say people tell me	▪ Direct when giving information
13	that unless I ask them you know. So if I was in a work environment what I don't like is to give people	▪ Does not like to make social errors

14	misleading information so because I don't understand the process of work sometimes and the language	▪ Feeling confused/ not understanding processes at work ▪ Asking people at work what she is or isn't allowed to say to clients ▪ Colleagues as social/ work guides ▪ Misinterpretations ▪ Making social errors/ mistakes ▪ Tendency to go off on a tangent ▪ Being directive in conversations at work ▪ Thinking and preparing ahead to be more effective ▪ Being prepared/ organised in advance helps ▪ Being prepared enables her to be clear in communication and own understanding ▪ Information gathering ▪ Sees no point in wasting own or others time ▪ Says whatever she wants to say.
15	used in work so I will ask them ok so is this what I'm allowed to say to that person, have I given them	
16	the right information, so I'm very consistent with my messages 'cos sometimes I can misinterpret that	
17	they've said this and I've got licence to do that and I'll run away with it, do you see what I mean? So,	
18	erm, in a work environment I will be directive but that's because I ask for it that's not because they tell	
19	me what to do it's because I want it and I want to make sure that I don't make several different phone	
20	calls for one thing. I wanna make sure that one phone call solves the whole problem cos I got the	
21	background information and I know exactly what I can offer and what I can't offer. So where they can	
22	go, what services they can go and speak to, so I'll do all that beforehand in the background before I	
23	even make a phone call because what's the point in making eight phone calls and wasting my day if I	
24	can do it all in one? Yeah, so that's what I do in my job, nobody tells me in my personal life what to say	
25	or what not to say. I say whatever I want. But my husband did try and tell me the other day that I	
26	mustn't say I've got Aspergers for the next time we apply for life insurance 'cos you don't have to tell	
27	everybody (laugh). He goes 'you don't have to tell everyone remember, that's what the consultant said.	
28	You don't have to tell everyone they don't need to know' (laugh). Its fine (laugh). So yeah there's one	
29	for that, but that's because he wants us to get life insurance (I: Hmm). Erm, but generally no like that	

30 31 32 33 34 35 36 37 38 49 40 41 42 43 44 45	there's two examples of things that have gone on recently, but no one else tells me what to say. When I was younger my mum gave me lots of advice about what to say to people, about how to manage friendships (I: Hmm). Erm, you know 'cos I always tell people too much information and she'd be like 'they don't need to know about that you know' in the end like, as I did tell them too much. They would just pick on me for telling them too much about myself anyway so I didn't really talk at all. So like when I was in secondary school I was very, very, quiet and I wasn't the teacher's pet. Erm, I wasn't the worst in the class. I wasn't the best in the class. I could be very good at being that, blending in (laugh). I blended in as much as possible. So I was like academically ok nobody bothered you know, what like asking me to do anymore, work or catch up on stuff, but then I never got asked to do any special tasks you know like the teacher's pet would. I would just sit there nice and quietly in class and then my mum would tell me like in friendships what I need to be saying and what I shouldn't be saying to people cos when I was about thirteen...(pause). No, twelve, twelve I might have been. I started my periods and erm my mum told me, they were so heavy, I fainted once they were really, really, heavy, I think at home and at school. So mum got erm put me on the pill didn't she, and she said don't tell anybody you're on the pill 'cos then they'll think that you're sleeping with loads of people you know, having sex with someone. So I had to keep my mouth shut then didn't I 'cos my mum was like 'that's not appropriate,	▪ Husband tells her what not to say in some instances following social errors ▪ Husband as social guide ▪ Learning from husband ▪ Mum would give advice on what to say ▪ Mum would give advice on friendships ▪ (Both – when younger) ▪ Mum as social guide ▪ Over-shares information with others ▪ Making social mistakes when younger ▪ Telling people too much ▪ Unaware of conversational etiquette ▪ Picked on/ Bullied at school ▪ Did not talk at school ▪ Passive ▪ Being quiet to go unnoticed ▪ Very, very quiet in secondary school ▪ Middle of the class ▪ Good at blending in ▪ Blending in as much as possible ▪ Academically steady ▪ Not the teacher's pet

46 47	you don’t want them to think that about you, you’re only twelve, thirteen, you’re not having sex with anyone’. So I had to make sure I kept that quiet. Mum was really adamant on that…	▪ Mum giving advice on what to say in friendships ▪ Being told what to say what not to say by mum

Word Count

FRONT COVER	**36**
SECTION 1	
Thesis Title	**10**
Thesis Abstract	**280**
SECTION 2	
Literature Review	**5,999**
(Excluding references & supplemental files; Including Figure 1, Appendix A)	
References, Appendices & Supplemental Files	6,090
SECTION 3	
Empirical Paper	**6,666**
(Excluding references, appendices & author note)	
References, Appendices & Author Note	2,852
SECTION 4	
Contributions to Theory and Clinical Practice	**3,258**
(Excluding references & appendices)	

References & Appendices	1,833
SECTION 6	
General Appendices	1,746
TOTAL	**16,259**

(Including front cover, thesis title & abstract; excluding references, appendices & supplemental files)

References, Appendices & Supplemental Files	12,521
OVERALL TOTAL	**28,780**