

The role of VIQ in the camouflaging of autistic traits

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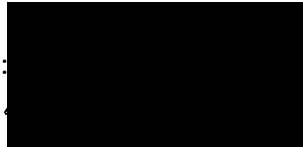
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Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signature:



Name: Benjamin Ross Hannon

Date: 19/06/2020

Overview

Part one is a systematic review of tools used to quantify social camouflaging in autism. The review searched three databases to identify such tools, and evaluated their psychometric properties using an established appraisal checklist.

Part two is a quantitative empirical study into the relationship between verbal intelligence and social camouflaging using three distinct, but related measures of camouflaging. The study controlled for executive functioning and autistic-like traits, in order to assess the unique predictive power of verbal intelligence.

Part three is a critical appraisal of the research process. It contains reflections at each stage, starting from choosing a thesis, to completing the literature review and empirical paper. Part three also considers use of the term ‘camouflaging’, before concluding with considerations for the future of social camouflaging research.

Impact Statement

Research into social camouflaging has become more common over the past five years, however there is no agreed method of measuring this construct. Moreover, the available methods had not previously been ratified in terms of their psychometric properties. The systematic review within this thesis investigated the psychometric properties of the available techniques used to measure social camouflaging in autism. The results indicated that the psychometric properties of the available measures are rated poorly when assessed by the COSMIN appraisal tool.

When considering the impact this systematic review will have within academia, there are multiple potential benefits. Most prominently, this review should prompt academics to consider whether the available camouflaging methods are fit for purpose. This is particularly pertinent in the area of reliability, where only one tool had investigated this. As such, the current measures of social camouflaging cannot *yet* be considered reliable. In addition, the systematic review should prompt researchers to consider the current taxonomy of the available measurement tools. Prior to the review, camouflaging measurement was broadly separated into ‘discrepancy’ and ‘observational/reflective’ methods. However, through the COSMIN appraisal process, it was clear that the psychometric properties of observational and questionnaire methods were starkly different. As such, academia should segregate observational/reflective into observational and questionnaire methods.

It is hoped that the current systematic review’s clinical impact will naturally follow on from the improvements in academia. By improving the reliability and validity of the available camouflaging measures, it is hoped that they will be better

placed for integration into clinical practice. At present, there are no available methods to help identify autistic individuals who may be camouflaging their autistic traits during a diagnostic assessment. Given that autism is diagnosed by behaviour alone, such camouflaging is particularly problematic for increasing missed diagnosis.

The empirical paper's finding of a relationship between VIQ and successful social camouflaging is hoped to shape future academic work across two areas. Firstly, this finding should stimulate researchers to continue exploring the cognitive profile of autistic teenagers who socially camouflage. Secondly, given the current findings of verbal intelligence differentially predicting successful camouflaging vs. camouflaging intent, researchers should now consider the specific aspects of camouflaging they are attempting to measure. It is possible that our current knowledge of social camouflaging, based upon the available research, may change as we seek to differentiate what aspect of camouflaging we are measuring.

Outside of academia, the research should now be utilised by clinicians, particularly within autism diagnostic services. In such services, it would be beneficial to incorporate intelligence testing to inform part of a holistic formulation, in the hope that this may reduce missed or misdiagnosis. Moreover, the findings should be disseminated to teachers, parents, and other primary care providers. It is possible that verbal ability is masking a true underlying social communication difficulty. As such, these professionals must carefully consider when to trigger the necessary assessment channels. In doing so, autistic children could enter services earlier and receive the support they are entitled to.

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Part 1: Literature Review

The psychometric properties of camouflaging measures: A systematic review.

Abstract

Aims: Social camouflaging has become an area of particular interest for autism researchers. This increased interest and subsequent research has led to a multiplicity of measurement tools that have been used to quantify camouflaging behaviour. However, to date, there has been little investigation into their psychometric properties. As such, the current systematic review aimed to identify and appraise all the available measurement tools used to quantify social camouflaging in autism.

Methods: A systematic search was conducted across PsychINFO, Web of Science, and ProQuest Dissertations to identify measurement tools from first publication to October 2019. Relevant measurement tools were appraised using the Consensus-based Standards for the Selection of Health Status Measurement Instruments (COSMIN) checklist.

Results: From the three databases searched, 13 studies met the inclusion criteria. Eleven unique measurement tools were identified. Results indicated that many of the available measurement tools are yet to demonstrate psychometric validity and reliability to provide confident and replicable outcomes.

Conclusions: It is recommended that social camouflaging researchers further refine the available tools. Increasing reliability and validity may help such methods to become integrated into clinical practice and potentially reduce missed or misdiagnosis.

Introduction

Background

Autism is a neurodevelopmental condition characterised by differences in social communication/interactions, sensory processing, and restricted interests (APA, 2013). The UK prevalence of autism is estimated to be around 1.1% (NHS information centre, 2012). Whilst autism is a relatively heterogeneous condition, there are no current biological markers for it. As such, its diagnosis is based upon the behavioural signs and symptoms, observable by qualified clinicians. The potential for this observational protocol to be impacted by social camouflaging is now coming to light.

The term ‘social camouflaging’ refers to both conscious and unconscious behaviours used to conceal autistic characteristics (Lai et al., 2011). The word ‘camouflaging’ is used to emphasise the attempt to blend into social environments and appear neurotypical (Dean, Harwood & Kasari, 2017). Examples of camouflaging behaviour include suppression or concealment of restrictive and repetitive behaviours or forced eye contact (Attwood & Grandin, 2006; Hull et al. 2017; Lai et al., 2011; Wiskerke, Stern & Igelstrom, 2018). Whilst the motivation to camouflage can depend upon a complex interplay between the individual and their environment (Cage & Troxell-Whitman, 2019), some common factors can be seen, including a desire to assimilate (i.e. to fit in) and connect with/relate to others (Hull et al., 2017). Despite the motivations for camouflaging appearing to hold potentially positive outcomes, the costs of such behaviour can be stark. Camouflaging has been reported to be effortful, and repeatedly linked with heightened stress, anxiety, depression, and suicidality (Boyd, Woodbury-Smith & Szatmari, 2011; Cassidy,

Bradley, Shaw & Baron-Cohen, 2018; Lai et al., 2011; Simone, 2010; Willey, 1999; Williams, 1992). More systemically, camouflaging one's autistic traits can lead to a late, missed, or misdiagnosis (Dworzynski, Ronald, Bolton & Happé, 2012; Lai & Baron-Cohen, 2015; Kopp & Gillberg, 1992), therefore limiting access to support services that would otherwise be provided.

Interest in social camouflaging has recently increased as more attention has been drawn to the known gender differences in diagnosis, with autistic women diagnosed less, and at a later age, despite equivalent autistic characteristics (Begeer et al., 2013; Duvékot et al., 2017; Dworzynski et al., 2012; Mandy et al., 2012). Camouflaging autistic traits was suggested to play a contributing role towards these differential diagnostic rates (Lai & Baron-Cohen, 2015). Attempts to explain this increased propensity for camouflaging in autistic females have included a different cognitive profile that supports camouflaging (Lehnhardt et al., 2016). Other explanations have included the potential for greater stigma towards autistic females who deviate from the male autistic stereotype, or conventional norms for female behaviour, which necessitate camouflaging strategies (Cage & Troxell-Whitman, 2019; Hull et al., 2017). Whilst there have been repeated findings of sex/gender¹ differences demonstrating increased camouflaging in females, attention has now turned away from this being a female only phenomenon. Both males and females are equally likely to spontaneously report camouflaging behaviour (Cage, Di Monaco & Newell, 2017), with quantification of camouflaging behaviour showing overlapping distributions between males and females (Lai et al., 2017; Lai et al., 2019).

Parallel to the emerging interest in social camouflaging, increased interest in the concept of 'compensation' for autistic traits has been evident (Livingston & Happé, 2017; Livingston, Colvert, Bolton & Happé, 2019). Much like camouflaging,

¹The current paper uses the term sex/gender to recognise that it is difficult to disentangle group differences that are driven by biological sex differences compared to culturally driven gender differences. 16

the goal with compensation is to mimic neurotypicality (Livingston, Shah & Happé, 2019). Theories of compensation propose that alternative cognitive pathways are used to compensate for difficulties during social interactions. An example of this might be the development of a conscious rule that, if others laugh at a non-literal statement in a social situation, this is likely to be a joke. Without laughter, this is likely an inaccuracy or even a lie (Livingston & Happé, 2017). As such, camouflaging and compensation appear to be two different perspectives of the same phenomenon, with the latter placing a strong emphasis upon the cognitive components used when attempting to conceal autistic characteristics. Because of this, the current review will consider the compensation literature alongside camouflaging research.

Measures of camouflaging

The novelty of social camouflaging research has led to an explosion of interest; however, current measurement methods are still being evaluated. With the multiplicity of tools, Hull, Mandy et al. (2019) proposed a taxonomy that differentiates discrepancy methods from observational/reflective methods. It should be noted that whilst some of these measures have attempted to quantify how much an individual is camouflaging, others have focused upon the contexts and motivations of camouflaging, or specific behaviours that may increase the likelihood of camouflaging.

Discrepancy methods

The defining feature of a discrepancy method is its attempt to quantify the difference between two different measurement tools; one of which is attempting to measure the

innate autistic characteristics of an individual, whilst the other is attempting to measure external presentation of autistic characteristics. Both scores are placed on an equivalent metric to enable one to be subtracted from the other. Large discrepancies between scores in the context of high innate autistic characteristics, but low external autistic presentation, is suggested to represent social camouflaging. Therefore, social camouflaging can be operationalised as a quantifiable gap between how autistic a person really is (i.e. their innate autistic characteristics), and how autistic they appear to others. Using this technique, group comparisons in the prevalence of camouflaging behaviour has been researched, along with the potential cognitive mechanisms that underpin camouflaging behaviour (Lai et al., 2017; Lai et al., 2019; Livingston & Happé, 2017).

Whilst this method was favoured early in camouflaging research, its use and potential utility may be limited. Discrepancy methods are reliant upon a single measurement of external autistic characteristics (i.e. during ADOS administration), with scores presumably impacted by camouflaging. However, given that the motivation to camouflage can change depending upon context, it is possible that autistic individuals, who may otherwise camouflage, would not do so during this assessment, resulting in low camouflaging scores. These low camouflaging scores are then interpreted as representing low camouflaging behaviour in all contexts. In addition, discrepancy methods can only measure camouflaging that is 'successful' in front of the assessing clinician or researcher during assessment of external characteristics. As such, an autistic person may attempt to camouflage (e.g. by withholding self-stimulatory behaviour) but be unsuccessful in doing so. The impact of this unsuccessful camouflaging is therefore missed. Discrepancy methods are also reliant upon measurement tools being able to assess how 'truly autistic' a person is,

in order to contrast this with how they appear. At present, there are no reliable biomarkers for autism, and the available measures are reliant upon reported signs and symptoms associated with autism, making it difficult to provide an adequate representation of 'true' autism. Finally, there is yet to be any investigation into the reliability or validity of such discrepancy methods.

Observation/reflective methods

An alternative to the aforementioned discrepancy methods is the observational/reflective approach. This refers to both questionnaires and direct observation. An example of direct observation can be seen with the work of Dean et al. (2017), who investigated autistic males' and females' behaviour in the playground. Whilst autistic females typically stood close to their peers, providing the impression of co-operative play, autistic boys spent more time alone. As such, females were deemed to blend in with typically developing children. One key advantage of this approach is that it enables an assessor to gauge camouflaging behaviour during a typical interaction, allowing peaks and troughs to be observed. However, this method relies upon the researcher or clinicians' judgement as to what constitutes camouflaging behaviour, opening up potential observer bias. Much like discrepancy methods, this technique also only provides a small snapshot of camouflaging behaviour, which is then extrapolated as a 'true' camouflaging score across time and place.

The use of camouflaging questionnaires as an alternative reflective approach can help circumvent some of the difficulties with potential observer bias. Such questionnaires (e.g. Hull, Mandy et al., 2019; Cage & Troxell-Whitman, 2019) require the rater to score their camouflaging behaviour on a pre-set scale, providing a

camouflaging score. These methods enable individuals to report upon their camouflaging in all contexts, whether this is successful or not. Potential confounds do however exist with these methods. It is possible that higher levels of autistic characteristics result in larger amounts of behaviours that are to be camouflaged (Hull, Mandy et al., 2019). As such, increased camouflaging scores may be indicative of one's 'autistic-ness'. Given that the rating is also reflective, and that camouflaging of autistic traits is hypothesised to happen at both the conscious and unconscious level, it is possible that the person is not aware of their own camouflaging. Much like discrepancy methods, many of the observational/reflective techniques are also yet to be comprehensively ratified in terms of their reliability and validity.

Review Questions

The increased interest and research into camouflaging, along with the potential for such research to reduce missed or misdiagnosis necessitates further questions about the reliability and validity of the currently available measures in the field of social camouflaging. To the author's knowledge, there have been no previous reviews investigating measurement tools associated with camouflaging.

Using a systematic review and critical appraisal, this review will address the following questions:-

- How do the current measurement tools attempt to measure camouflaging?
- What are the psychometric properties of the tools?
- How have these methods been created, and who with?
- How are these measurement tools interpreted?

Method

Search strategy

Three databases were searched for relevant articles. PsychINFO and Web of Science were used to investigate a psychology specific and a general science database, respectively. Due to the emerging nature of the camouflaging literature, ProQuest Dissertations was also used to investigate unpublished theses.

All databases were searched from first publication to October 2019. The search terms included [autis*] AND [camouflag*] OR [mask*] OR [compensat*] OR [pass*]. The search terms were chosen because camouflaging autistic traits is thought to involve both compensation and masking. The term 'passing' reflects its use in prior literature to refer to an autistic individual 'passing' as neurotypical.

The review also included manual searches of the reference lists of fully accessed articles. Experts researching camouflaging were also contacted, as necessary.

Inclusion and exclusion criteria

Studies were included in the current review if:-

- They attempted to measure the camouflaging of autistic traits directly, regardless of diagnostic status.
- They report measuring specific behaviours that increase the likelihood of successful camouflaging, regardless of diagnostic status.
- The outcome variables were either quantitative and/or categorical.
- The research was published in English.

There were no age limits for inclusion, and no time limits for publication were imposed.

Study selection process

To determine whether the inclusion criteria were met, all records were screened using a three-phase process. The initial search returned 5792 unique articles when using the ‘all fields’ search function. As such, phase one involved searching within the title, abstract, and key words only, using the search terms previously mentioned. Following phase one, the remaining titles and abstracts were gleaned for basic relevance to the camouflaging of autistic traits. The final phase involved accessing the remaining articles in full and excluding those that did not meet the inclusion criteria previously. Each stage is outlined in figure 1 (below).

Quality appraisal tool

The Consensus-based Standards for the Selection of Health Status Measurement Instruments (COSMIN) checklist (Mokkink et al., 2010) was used to critically appraise the camouflaging measurement methods. The COSMIN checklist contains 102 total items. Ninety-eight items assess the psychometric quality of the measurement instrument across nine measurement properties (see table 1 and Appendix A). All of the included items in the COSMIN checklist were agreed through a four-round international Delphi study, with experts in the field of psychology, epidemiology, statistics, and clinical medicine contributing. The checklist requires the user to *only* assess the properties that are reported by the authors, or those that are relevant to the measurement instrument. For example, if responsiveness of the instrument is not reported or applicable, this would leave eight

measurement properties to be assessed. The current review utilised the updated four-point scoring system for the COSMIN (Terwee et al., 2012). All 98 psychometrically relevant items are scored along a four-point scale, ranging from ‘excellent’ and ‘good’, through to ‘fair’ and ‘poor’. The nine measurement properties subsequently receive an overall rating along the same four-point scale, using a ‘worst score counts’ methodology, meaning that the lowest rated item within each measurement property reflects the overall rating.

Each camouflaging tool was assessed by reading the associated paper twice, and subsequently rating them using the COSMIN checklist². Where information from the paper was ambiguous or unclear, the corresponding author was contacted.

Due to the fledging nature of camouflaging research, content validity was not possible to evaluate in its entirety, given that there is no universally-agreed criteria for all of the aspects of camouflaging. As such, item four from the construct validity property (‘was there an assessment of whether all items together comprehensively reflected the construct measured’) was omitted, leaving 113 total items.

²In the current context of a DClinPsy thesis, the resources were not available for two researchers to independently complete the literature search and COSMIN evaluation. However, it is recognised that this would represent best practice.

Table 1

COSMIN checklist measurement properties and definitions

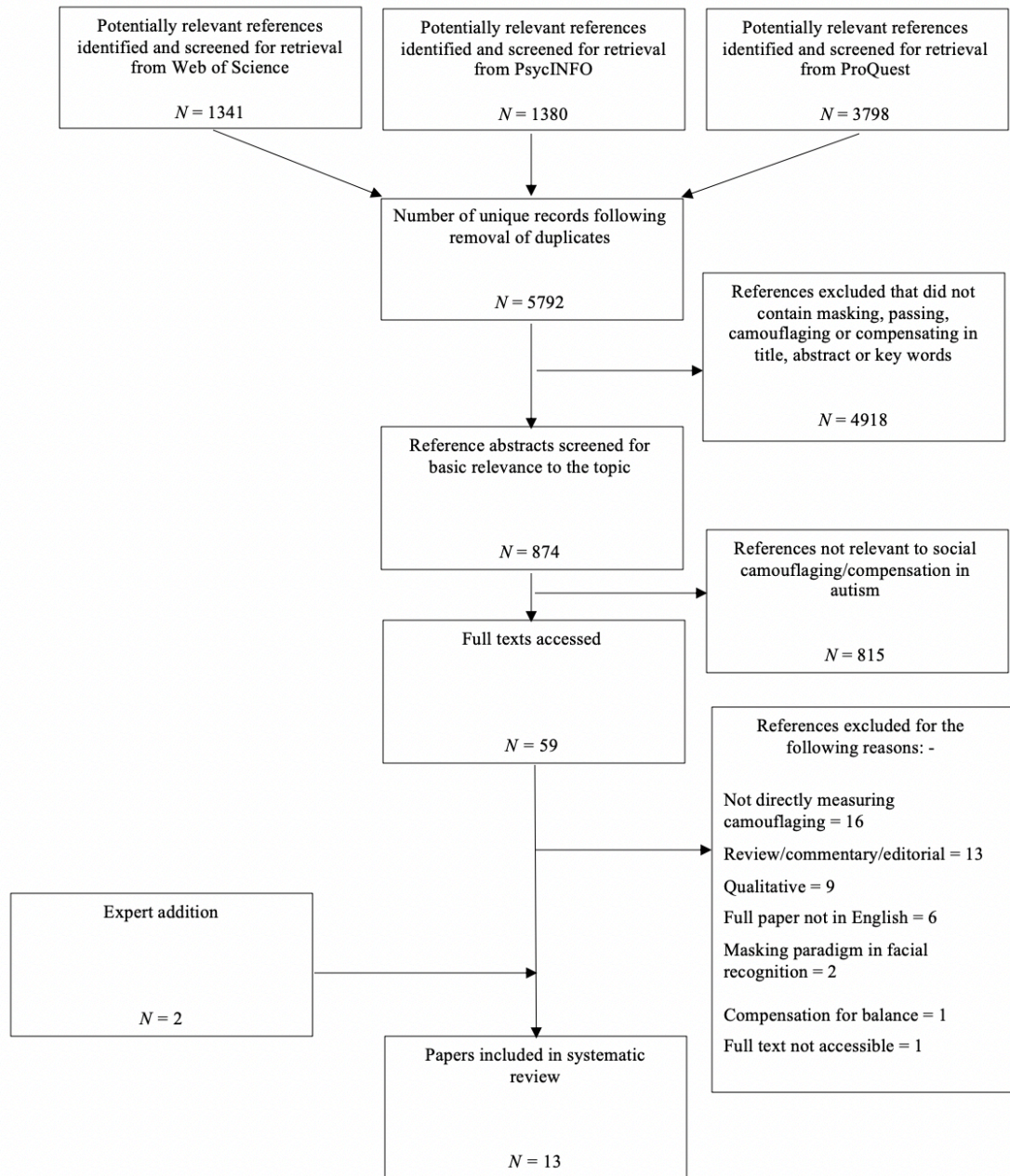
Measurement property	Definition	Number of measurement items
Internal consistency	The extent to which items on the measurement tool are interrelated	11
Reliability	The degree to which scores from participants who have not changed are the same under repeated measurements.	14
Measurement error	The amount of random error that is not due to changes in the variable of interest	11
Content validity	The extent to which the measurement instrument is measuring what it reports to measure	5
Structural validity	How much the measurement tool reflects the dimensionality of the construct under measurement	7
Hypothesis testing	The extent to which the measurement tool responds as expected under hypothesis testing conditions	10
Cross cultural validity	The degree to which the measurement tool adequately reflects the original measurement tool, after translation	15
Criterion validity	The degree to which the measurement tool performs with a pre-set criterion	7
Responsiveness	The ability for a measurement tool to detect change, in the context of true changes in the construct of interest	18

Results

Figure one (below) documents the review process from first identification, through the previously mentioned three-phase screening process. From the initial 5792 studies identified, 874 contained information relating to masking, passing, camouflaging or compensating in autism within the title, abstract or key words. After screening the abstracts, 59 studies were deemed to have basic relevance to camouflaging. Eleven met the inclusion criteria. Two further studies were identified by experts within the field of social camouflaging as relevant (one unpublished, and one containing a subscale relating to masking, which was part of a larger autism questionnaire).

Figure 1

Study inclusion flow diagram highlighting three-phase process from identification to inclusion



Demographic data

Table two (below) includes the studies included in the review. Where a measurement tool has been named, this will be used. For measures that have not been named, these will be referred to according to the lead authors name. From the 13 included studies, four (30.8%) utilised a discrepancy method to measure camouflaging. Of these four studies, three unique discrepancy methods were used. The remaining nine studies (69.2%) used an observational/reflective approach. Of these nine studies, eight unique methods were used.

Eight (61.5%) of the included studies were completed within the UK; three (23.1%) in the USA, one (7.7%) in Australia, and one (7.7%) in Poland.

Diagnostic status varied across each study. Five (38.5%) were completed exclusively with autistic individuals. Six (46.1%) were completed with a mixed sample of autistic and neurotypical participants. One (7.7%) was completed with parents of autistic children, and one (7.7%) was completed with presumed neurotypical individuals, only.

In terms of age, six (46.1%) studies were completed exclusively with adults (i.e. equal to, or over, 18 years old). Four (30.8%) were completed exclusively with children. One study was completed with a mix of adults and children (7.7%), one with parents, and one study reported mean age without giving a range, making their age of inclusion unclear.

When considering the sex/gender distribution of the 3231 participants included in the review, 42.1% classified themselves as male, 52.7% identified as female, and 5.2% either identified as neither male or female, or did not wish to disclose.

Table 2

Publication, name of measure, type of measure and demographic information for included studies

Publication	Name of measure	Type of measure	Group	N	Age	Sex (male/female/other)	Country of study
Cage & Troxell-Whitman (2019)	The Cage Questionnaires	Observational/reflective	autism spectrum, Asperger syndrome, PDD-NOS	262	>18 y/o $M = 33.62$	111/135/12	UK
Cassidy et al. (2018)	The Cassidy Questionnaire	Observational/reflective	autistic and non-autistic	164 autistic 169 non-autistic	20-60 y/o	autistic: 65/99 non-autistic: 54/115	UK
Dean, Harwood & Kasari (2017)	The POPE	Observational/reflective	autistic and non-autistic	48 autistic 48 non-autistic	autistic boys $M = 7.71$ autistic girls $M = 7.75$ non-autistic group $M = 7.92$	autistic: 24/24 non-autistic: 24/24	USA
Hull, Mandy et al. (2019)	CAT-Q	Observational/reflective	autistic and non-autistic	354 autistic 478 non-autistic	autistic: 16-82 y/o non-autistic: 18-75 y/o	autistic 108/179/67 non-autistic: 192/255/31	UK
Hull, Lai et al. (2019)	CAT-Q	Observational/reflective	autistic and non-autistic	306 autistic 472 non-autistic	autistic male $M = 46.68$ autistic female $M = 39.91$ autistic non-binary $M = 33.50$ non-autistic male = 30.94 non-autistic female = 29.86 non-autistic non-binary = 26.52	autistic: 108/182/16 non-autistic: 193/252/27	UK
Ladha & Cole (2018)	The CSSQ	Observational/reflective	non-autistic	247	18-62 y/o $M = 21.69$	49/184/14	UK
Ormond et al. (2018)	The Q-ASC	Observational/reflective	parents of autistic children	236	5 – 19 y/o	138/98	Australia

Parish-Morris et al. (2017)	The Parish-Morris Method	Observational/Reflective	autistic and non-autistic	65 autistic 17 non-autistic	6-17 y/o autistic $M = 9.96$ non-autistic $M = 11.32$	autistic: 49/16 non-autistic: 8/9	USA
Lai et al. (2017)	The Lai Method	Discrepancy	autistic	60	18 – 49 y/o male $M = 27.2$ female $M = 27.8$	30/30	UK
Lai et al. (2019)	The Lai Method	Discrepancy	autistic and non-autistic	57 autistic 62 non-autistic	18 – 45 y/o autistic male $M = 26.59$ autistic female $M = 28.19$ non-autistic male $M = 27.94$ non-autistic female $M = 27.63$	autistic: 29/28 non-autistic: 33/29	UK
Livingston et al. (2019)	The Livingston Method	Discrepancy	autistic	136	10-15 y/o $M = 13.28$	112/24	UK
Rynkiewicz et al. (2016)	The Rynkiewicz Method	Observational/Reflective	autistic	33 (26 analysed)	5 – 10 y/o	16/10	Poland
Schuck, Flores & Fung (2019)	The Schuck Method	Discrepancy	autistic	28	male $M = 23$ female $M = 33$	17/11	USA

PDD-NOS : Pervasive Developmental Disorder – Not Otherwise Specified; POPE: Playground Observation of Peer Engagement; CAT-Q: Camouflaging Autistic Traits Questionnaire; CSSQ: Conscious Social Strategies Questionnaire; Q-ASC: Questionnaire For Autistic Spectrum Condition.

Quality appraisal

None of the included studies investigated cross-cultural validity, criterion validity or responsiveness, which are part of the COSMIN checklist. These domains have therefore been omitted from subsequent tables. For ease of comparison, discrepancy methods and observation/reflective methods will be discussed separately.

Discrepancy methods

The COSMIN ratings for the available discrepancy methods are detailed in table three (below).

Table 3

COSMIN checklist ratings for the available discrepancy methods

Name of measure	Internal consistency	Reliability	Measurement error	Content validity	Structural validity	Hypothesis testing
The Lai Method	●	●	●	●	●	●
The Livingston Method	●	●	●	●	●	●
The Schuck Method	●	●	●	●	●	●

Key

- Excellent
- Good
- Fair
- Poor
- Not assessed

The Lai Discrepancy Method - (Lai et al., 2017 & Lai et al., 2019)

The Lai discrepancy method was one of the first methods to attempt to measure camouflaging. The method used the AQ (Baron-Cohen, Wheelwright, Skinner et al., 2001) and 'Reading the Mind in the Eyes' test (RMET) (Baron-Cohen, Wheelwright, Hill, Raste & Plumb, 2001) as indicators of internal autistic status. External presentation was quantified using the ADOS (Lord et al., 2000). It should be noted that during original use of the Lai method in the 2017 publication, the authors used the Western-Psychological Services (WPS) published 'diagnostic algorithm score', reflecting social interactive and communicative behaviours associated with autism. Comparatively, the 2019 publication used the updated Social Affect domain score from the ADOS (Hus & Lord, 2014). Whilst suggesting potentially two different methods, the Lai et al. (2019) repeated their analysis using the original WPS method, with consistent findings.

The Lai method requires the three scores (AQ, RMET, & ADOS) to be standardised by mean centring to the sample and scaled using the maximum available score. The AQ score is then subtracted from ADOS, creating a first camouflaging score (CF1). The RMET score is then subtracted from the ADOS to create a second camouflaging score (CF2). Both scores are included in a Principle Component Analysis (PCA) to create an overall camouflaging score using the first principle component. Higher scores are indicative of greater camouflaging. The Lai method has been used to investigate between sex differences in camouflaging, along with its cognitive and neural correlates.

When rated by the COSMIN checklist for structural validity, the technique was rated as 'good' due to the incorporation of PCA. This enabled Lai et al. to use

the pattern of performance across both internal autistic status tasks when creating their camouflaging score, rather than relying on a single metric.

The method was also rated as ‘good’ for hypothesis testing. This is a key advantage with the Lai method, as the technique provides a single parsimonious score of camouflaging that can be utilised to test hypotheses of group difference (e.g. females camouflage more than males) or potential covariates of camouflaging (e.g. camouflaging and executive functioning).

Where the Lai method was rated less well was in the domain of reliability and measurement error, where it was deemed to be poor. Only one measurement was completed in both published studies, making it impossible to calculate potential variability in scores. Moreover, there appeared to be no attempt to understand inter-rater reliability as there were no indications of the ADOS being scored by more than one person, or completed by more than one researcher, across participants.

The Livingston Discrepancy Method – Livingston et al. (2019)

The Livingston discrepancy method was created to identify and categorise the extent to which autistic individuals are engaging in compensation behaviour. Similar to Lai et al. (2017; 2019), the technique attempts to quantify innate autistic characteristics (referred to by the authors as social cognitive ability) and compare this with external autistic presentation, using the ADOS (Lord et al., 2000). However, unlike Lai et al., the authors used the Frith-Happé animation task (Abell, Happé & Frith, 2000), which assesses theory of mind (ToM), as a proxy for internal autistic status. In addition, unlike Lai et al. (2017; 2019) the Livingston method used the results to create a categorical classification of individuals into four pre-assigned groups, rather than providing a continuous score. This was achieved by conducting a median split from

the data of a typically developing group, classifying autistic individuals as having either ‘good’ or ‘poor’ theory of mind from the Frith-Happé task. Participants are also split into a ‘good’ or ‘poor’ ADOS group, using a median split of the sample. Using the classifications on these two tasks, participants could be rated as ‘high compensators’ (good ADOS, poor ToM), ‘low compensators’ (poor ADOS, poor ToM), ‘deep compensators’ (good ADOS, good ToM), or ‘unknown’ (poor ADOS, good ToM). The method has been used to investigate between group differences on areas such as IQ, executive function, and anxiety.

Using the COSMIN checklist, this method received its highest score in the hypothesis testing domain, where it was scored as ‘fair’. This would have been rated higher, however, the authors did not declare their expected hypotheses prior to the analysis.

As with the Lai method, reliability was rated as poor. The authors were not able to demonstrate inter-rater, test-retest, or intra-rater reliability. This lack of repeated measurements also impacted the ability to gauge measurement error, meaning that the Livingston method was rated poor on this domain also.

The Schuck Method – Schuck, Flores & Fung (2019)

The Schuck method sought to replicate the findings of Lai et al. (2017) using a North American sample. However, it should be noted that the technique differs slightly from the Lai method. Namely, the Schuck method does not utilise the RMET. Because of this, there is no need to use PCA to create a single camouflaging metric. The camouflaging scores in the Schuck method are therefore created by mean centring data from the ADOS, and subtracting this from a mean centred AQ score, enabling the creation of a “CAM” score. Higher scores are indicative of greater

camouflaging. The method was used to investigate between sex differences in camouflaging levels, as well as potential covariation between camouflaging, working memory and emotional expressivity.

The COSMIN checklist rated the Schuck method as poor in all assessable domains. Whilst the method facilitated between group comparisons, the small sample size impacted its rating in the hypothesis testing domain. In addition, the method was rated as poor in terms of reliability and measurement error, with no information related to repeated testing, double coding of ADOS results, or inter/intra-rater reliability checks.

Observation/reflective methods

The COSMIN ratings for the available observation/reflective methods are detailed in table four (below).

Table 4

COSMIN checklist ratings for the available observation/reflective methods

Name of Measure	Internal consistency	Reliability	Measurement error	Content validity	Structural validity	Hypothesis testing
The Cage Questionnaires	●	●	●	●	●	●
The Cassidy Questionnaire	●	●	●	●	●	●
CAT-Q	●	●	●	●	●	●
The POPE	●	●	●	●	●	●
CSSQ	●	●	●	●	●	●
Q-ASC	●	●	●	●	●	●
The Parish-Morris Method	●	●	●	●	●	●
The Rynkiewicz Method	●	●	●	●	●	●

CAT-Q: Camouflaging Autistic Traits Questionnaire; POPE: Playground Observation of Peer Engagement; CSSQ: Conscious Social Strategies Questionnaire; Q-ASC: Questionnaire For Autistic Spectrum Condition

Key

- Excellent
- Good
- Fair
- Poor
- Not assessed

The Cage Questionnaires – Cage & Troxell-Whitman (2019)

The Cage Questionnaires are two separate questionnaires that do not seek to measure camouflaging behaviour directly, but instead investigate the contexts in which it occurs, and the reasons as to why someone would camouflage. The authors based these two questionnaires upon ‘disconnect theory’ (Ragins, 2008). This theory posits that individual behaviour relies upon contextual dependent information. As such, behaviour will shift and change depending upon the context in which someone is placed.

The ‘camouflaging reasons questionnaire’ presents 21 statements requiring agreement or disagreement across a five-point Likert-scale. Two principle components were extracted from the questionnaire. The first was labelled ‘conventional reasons’ (where camouflaging serves a primary function in an education or occupational context), whilst the second was named ‘relational reasons’ (when camouflaging aids interpersonal interactions). This questionnaire has been used to investigate potential group differences between males and females in terms of camouflaging reasons.

Similarly, the camouflaging contexts questionnaire was comprised of 22 common contexts for camouflaging, with respondents indicating how often they camouflaged in that context, along a five-point Likert-scale. Two components were extracted from this questionnaire, including ‘formal contexts’ (e.g. work/school), and ‘interpersonal contexts’ (e.g. when with friends or family). The contexts questionnaire has been used to categorise individuals who camouflaged on either a consistently low, consistently high basis, or those that switched between high and low camouflaging depending upon context. This has enabled between group comparisons in levels of anxiety and stress.

In terms of the COSMIN checklist, the questionnaires were rated as ‘excellent’ for content validity. This rating was aided by the incorporation of individuals from the autistic community in the creation of the questionnaires.

The questionnaires were rated as ‘good’ in terms of their structural validity. This reflected the use of exploratory factor analysis, and would have been rated higher if the number of missing items from the original sample were reported, which forms part of the basic design requirements for higher scores on the COSMIN.

Hypothesis testing was also rated as ‘good’, as authors provided some hypotheses. However, ratings were hampered by the authors not describing *a priori* the direction of their expected group differences.

Internal consistency of both questionnaires was rated as poor. Whilst the internal consistency statistics were provided for both questionnaires, they were not reported for each of the components within the contexts and reasons questionnaires. In addition, the number of missing items, and how to deal with missing items were not reported.

The Cage Questionnaires were rated as ‘poor’ in terms of reliability and measurement error. The questionnaires were only administered once. Calculation of measurement error and test-retest reliability was therefore not possible. With specific reference to the contexts questionnaire, without retest data, it is unclear whether participants would remain in their assigned groups of consistently high, consistently low, or switchers, were the questionnaire to be administered again.

The Cassidy Questionnaire – Cassidy et al. (2018)

The Cassidy Questionnaire was designed to investigate the tendency for someone to camouflage, and use this score to assess a potential association with suicide in

autistic individuals. The questionnaire comprises four questions. Participants are asked to respond whether they have tried to mask or hide their autistic symptoms. Those responding yes are required to report in what contexts it occurs; how often they camouflage, and the overall amount of the day they spend camouflaging. Scores are calculated as the sum of overall areas (out of 8), frequency (out of 6) and amount (out of 6). Total camouflaging scores are calculated out of 20.

The questionnaire was rated as 'fair' for the hypothesis testing domain. This could have been rated higher if it were clear how missing items were handled. In addition, the authors were unclear as to the directionality of their expected outcomes, i.e. whether suicidality may increase or decrease in relation to camouflaging.

The questionnaire was also rated 'poor' in terms of internal consistency. This could have been rated higher; however, the authors did not meet basic design requirements by providing instructions on how to handle missing items.

When rating structural validity, the Cassidy questionnaire was assessed as 'poor'. Factor analysis was not used in the creation of the questionnaire.

Reliability and measurement error were also rated as 'poor'. The authors did not seek to understand test-retest and inter-rater reliability by administering the questionnaire on a second occasion. This also prevented assessment of measurement error.

Content validity of the Cassidy questionnaire was rated as poor. This was mostly due to the authors providing no information as to how they attempted to cover the main concepts of camouflaging (e.g. through qualitative research or service user consultation).

The Camouflaging of Autistic Traits Questionnaire (CAT-Q) – Hull, Mandy et al. (2019) & Hull, Lai et al. (2019)

The CAT-Q was born out of qualitative research into the nature, motivations, and consequences of camouflaging autistic traits (Hull et al., 2017). It is used as a self-report measure of camouflaging, using 25-items, with responses across a 7-point Likert-scale. The questionnaire consists of three subscales: compensation (strategies used to compensate for social difficulties), masking (hiding of autistic characteristics or portrayal of neurotypical behaviour), and assimilation (attempts to fit into social situations). It has previously been used in two studies identified during the review process, once for development and validation purposes (Hull, Mandy et al., 2019), and once to investigate gender differences in camouflaging (Hull, Lai et al., 2019).

The questionnaire's best rating on the COSMIN checklist came in the content validity domain, where it was rated 'excellent'. This was due to the use of prior qualitative research when creating the questionnaire.

Unlike other measures of camouflaging, the CAT-Q was administered to subgroup of participants on a second occasion. This enabled reliability and measurement error to be assessed. The CAT-Q was rated as 'fair' on these domains. This would have been higher; however, the authors did not provide information about how missing items were handled.

The CAT-Q was also rated as 'fair' in terms of internal consistency, structural validity, and hypothesis testing. Whilst the questionnaire reported their Cronbach's alpha statistic, along with conducting exploratory and confirmatory factor analysis, the basic design requirements for each of these properties necessitates information on how missing items are handled, limiting higher ratings.

The Playground Observation of Peer Engagement (POPE) – Dean et al. (2017)

The POPE is a measurement tool that investigates camouflaging through the medium of its impact on playground interactions. It has been used to observe children in the playground and classify behaviour into pre-assigned categories (Kasari, Locke, Gulsrud & Rotheram-Fuller, 2011; Kasari et al., 2016). For the purposes of measuring camouflaging, three observation categories are used: game (child is actively playing a game with another), joint engagement (child is socialising with others), and solitary (child is alone). Each child is classified as being within one of these three states every one minute, across a 10-15-minute observation period. The POPE has been used to compare autistic and non-autistic children, across sex and diagnostic status, in terms of time spent within each observation category. Dean et al. (2017) observed frequent weaving in and out of joint attention for autistic girls, which the authors interpreted as camouflaging.

Within the hypothesis testing domain, the POPE was rated as ‘fair’. The authors provided clear *a priori* hypotheses about the expected differences between boys and girls in terms of camouflaging related playground interactions. This rating would have increased to good, however, the basic design requirement of how missing data is handled was not provided.

With regards to reliability, the POPE was rated as ‘poor’. The authors did not repeat similar observations of the same children at a different time point. However, it should be noted that the authors were able to demonstrate good inter-rater reliability, with two raters coding 25% of the observations, producing an inter-rater reliability statistic over .90.

The Conscious Social Strategies Questionnaire (CSSQ) – Ladha & Cole (2018)

The CSSQ was developed at Bangor University with the intention of measuring camouflaging behaviour in autistic individuals. The questionnaire consists of 15 items derived from prior qualitative research (Bargiela, Steward & Mandy, 2016; Hull et al., 2017) rated across a five-point Likert-scale. The questionnaire contains four factors, including: masking strategies (i.e. hiding autism characteristics), avoidance-based strategies (i.e. limiting social interactions), compensation (i.e. strategies used to compensate for social difficulties), and absence of strategies. The original paper has reported upon the development and validation of the questionnaire only. It has not been used for group comparisons.

The CSSQ received its best ratings in the internal consistency, structural validity and hypothesis testing domains; all of which were rated as ‘fair’. In terms of internal consistency, this rating was achieved by calculating Cronbach alpha for each subscale of the measure, whilst the rating for structural validity was achieved by incorporating factor analysis into the research. Comparatively, hypothesis testing achieved a rating of fair as the expected hypotheses of the authors was deducible. However, all three domains were limited from achieving higher ratings as the authors did not meet basic design requirements by reporting how missing items were handled.

In terms of construct validity, the questionnaire was rated as ‘poor’. This was due to the validation sample not being completed with autistic individuals. The questionnaire has therefore not been validated in the sample with which it is intended to be used.

A lack of repeated administration led to the questionnaire receiving a rating of ‘poor’ on the reliability and measurement error domains.

The Questionnaire for Autism Spectrum Conditions (Q-ASC) – Ormond, Brownlow, Garnett, Rynkiewicz & Attwood (2018)

The Q-ASC is a questionnaire that was not specifically developed to measure camouflaging. Instead, it is a measure of broader autism symptomology, rated by parents of five to 19-year olds, with a subscale that is specific to social masking. The subscale is comprised of five questions, with example items including ‘does his/her facial expression sometimes not match his/her mood, or the situation?’, rated along a four-point Likert-scale. Using this data, the authors were able to compare social masking between sexes.

The Q-ASC social masking subscale received a rating of ‘good’ in the internal consistency domain of the COSMIN. This rating would have been improved to ‘excellent’, however, the small number of items within the subscale prevented a higher rating.

The subscale was also rated as good in terms of structural validity. This was aided by the use of exploratory factor analysis. Once again, the small number of items within the subscale prevented it from receiving a higher rating. The subscale was rated as ‘good’ in terms of hypothesis testing.

The subscale was rated less well in terms of reliability and measurement error, with the questionnaire only being administered at one time point. As such, the COSMIN rated this as ‘poor’.

The subscale was also rated as ‘poor’ within the content validity domain. However, this reflects the questionnaire being created to assess gendered presentations of autistic behaviour, rather than camouflaging specifically.

The Parish-Morris Method - Parish-Morris et al. (2017)

This Parish-Morris method is unlike any other, as it focuses specifically upon linguistic strategies that can contribute towards successful social camouflaging. The method investigates filled pauses, differentiating between ‘UH’ (which is used to signal a short delay), and ‘UM’ (which is used to signal more significant delays). For autistic children, lower use of ‘UM’ is associated with autistic symptomology. When focusing upon sex and diagnosis, Parish-Morris et al. (2017) found that autistic girls, and typically developing children have high ‘UM’ ratios when compared to autistic boys during the ADOS. These findings were interpreted as a demonstration of linguistic camouflaging, providing females with the opportunity to blend in with their typically developing peers.

On the COSMIN, the Parish-Morris method was rated as ‘good’ in terms of hypothesis testing, due to the authors providing reasonable *a priori* hypotheses. However, the relatively small sample size prevented a higher rating on this domain.

Like many of the other methods, the Parish-Morris method was rated as poor in terms of reliability, as data was only available once for each child.

The Rynkiewicz Method – Rynkiewicz et al. (2016)

The Rynkiewicz method was first used in Poland to investigate non-verbal behaviours that may facilitate successful social camouflaging. It was developed with five to 10-year-old children during the ADOS demonstration tasks. The child’s head, neck, shoulder, elbow, wrist, palm, and finger movements were tracked using a Microsoft Kinect sensor system. This enables comparison between groups for vividness of gestures (i.e. shorter time of gesture, but increased length). Increased vividness was interpreted as camouflaging other autistic diagnostic features.

The Rynkiewicz method was rated as 'fair' in terms of hypothesis testing, as some expected effects were described. This would have been rated higher; however, it was unclear how missing data was handled. For example, if the Kinect software stopped tracking momentarily, the authors did not report how much data would be unusable.

In terms of reliability, the method was rated as 'poor'. The authors administered this method at one time point, providing limited information on test-retest reliability.

Discussion

This review identified thirteen papers that attempted to measure the camouflaging of autistic traits. Three related, but distinct discrepancy methods, and eight distinct observational/reflective methods were identified. When assessed with a critical appraisal tool, many of the currently available methods were yet to be assessed in terms of their basic psychometric properties. Whilst preliminary validity of the measurement tools was demonstrated with some questionnaires, only one measurement tool attempted to demonstrate test-retest reliability. As such, it is clear that the current tools for measuring camouflaging should be further investigated before continued research into camouflaging takes place.

Discrepancy methods

The discrepancy methods identified here demonstrated potential strengths in terms of their ability to test hypotheses. That is, they either categorise individuals into groups to facilitate further comparison on another variable (The Livingston method), or

provide a quantitative score of camouflaging that opens up general linear modelling (GLM) methods of analysis (The Lai & Schuck methods). Unique to the Lai method, there was demonstrable structural validity. The use of two internal measures enabled the researchers to reduce their reliance on one internal measure of autistic status.

Whilst the strengths of discrepancy methods imply that they have potential utility in future camouflaging research, and/or clinical environments, it should be emphasised that evidence for validity of measurement was lacking. Often, inter-gender differences on these measures were ascribed to camouflaging, and therefore could be mistaken as indicators of validity (i.e. if females score higher, then the score represents camouflaging rather than other potential inter-gender differences in autistic presentation). Both the Lai and Schuck methods created their camouflaging metric and measured sex differences between males and females. Whilst group differences were presumed to represent camouflaging, it is not clear as to whether these may have also been driven by a third variable, such as the differential presentation due to the broader female autism phenotype (Bargiela et al., 2016), rather than camouflaging *per se*. The inability to judge discrepancy methods in terms of content validity reflects this difficulty in confidently ascribing the internal vs external autistic gap as camouflaging.

Despite the Livingston method facilitating group comparisons between the different classifications of compensators (high, low, deep or unknown), information relating to the validity of these groups was lacking. Group allocation was based upon preconceived compensation criteria. For example, if someone scores ‘good’ on the ADOS, and ‘good’ on a measure of ToM, they are ‘deep compensators’. Those classified as ‘deep compensators’ are believed to have flexible compensatory processes that are more sophisticated than their high compensating peers, whose

poorer performance on ToM tasks (whilst maintaining good performance on the ADOS) reflects inflexibility in compensation strategies. The authors did not seek to demonstrate that deep compensators and high compensators differed in the flexibility of compensation behaviour, which is predicated by their methodology. As such, it is currently unclear as to what these groups represent, and how this translates into the lives of autistic individuals. Further research into these group differences using the Livingston method is now strongly recommended to improve its content validity.

Whilst content validity was not assessable for any of the discrepancy methods, it is important to consider the incorporation of the Frith-Happé animation task (Abell et al., 2000) during The Livingston Method. This task was designed to investigate ToM. The use of this task within the current context, as a proxy for social-cognitive ability, can be seen to over privilege the cognitive elements of autism, whilst neglecting social skills and communicative ability. As such, future use of the Livingston method may wish to consider incorporating an alternative proxy measure of social-cognitive ability.

None of the available discrepancy methods demonstrated reliability of measurement. The three discrepancy methods were only administered at one time point, limiting test-retest reliability information. Potential differences in terms of item scoring between assessors during administration of the ADOS, which is known to vary (Zander et al., 2016), was not reported. As such, inter-rater reliability was not quantifiable. It is highly recommended that the reliability of discrepancy measures be further researched, before being relied upon as a single measurement of camouflaging.

Observation/reflective methods

From the available observational/reflective methods, there was some demonstrable content validity. The CAT-Q and Cage Questionnaires received ratings of ‘excellent’ in this domain. In the case of the CAT-Q, this was due to the incorporation of qualitative research from Hull et al. (2017) when the questionnaire was created. Comparatively, the Cage Questionnaires obtained their rating by including individuals from the autistic community into the creation of the questions. All other observational/reflective approaches were rated as ‘poor’ in terms of content validity. Given the early stages of research into camouflaging, it would be strongly recommended that researchers seek to base their measures on information from experts by experience at all stages of the measurement development process.

Much like the discrepancy methods, many of the observation/reflective methodologies scored well in the domain of hypothesis testing. The available measures were able to make *a priori* hypotheses that facilitated GLM based statistical analysis. However, it should be noted that many of the hypotheses were based upon group differences (e.g. females camouflage more than males) or associations between camouflaging scores and another constructs (e.g. camouflaging and anxiety). Following further development of the camouflaging measures, future research may now wish to extend this hypothesis testing into future predictions of outcome variables to investigate the long-term impact of social camouflaging.

Of all the available camouflaging measures, only the CAT-Q sought to administer their measurement on two different occasions. This enabled the questionnaire to be ratified in terms of its test-retest reliability and measurement error. Whilst the CAT-Q received a rating of ‘fair’ in these domains, it should be emphasised that this would have been higher, had the researchers met the basic

design requirements of how to handle missing items. As such, it is strongly recommended that the creators of the CAT-Q provide information about missing items to further improve its psychometric properties.

Representation – who were the measures created with?

The currently available methods incorporated a variety of demographics within their research. When considering age, the majority of methods focused exclusively on children (e.g. POPE & The Rynkiewicz Method), or exclusively on adults (e.g. The CSSQ & The Cage Questionnaires). At present, only one measure has been used with both children and adults, with the upper age range being 19 years old (Q-ASC). Whilst this may appear to be a limitation of the available methods, it should be recognised that camouflaging can change as a function of age (Jorgenson, Lewis, Rose & Kanne, 2020). As such, the currently available methods may wish to investigate their use across age ranges, or whether they should be considered exclusive to adults or children.

As previously recognised (c.f. p.16), interest in camouflaging began with females, but has since expanded. Of the currently available research, 42.7% of participants identified as male, 53.5% female, and 3.8% did not disclose. Whilst this represents broad equality in terms of sex/gender representation, it should be noted that some research contained heavily skewed samples. For example, The Livingston Method sample contained 82.4% males; comparatively the CSSQ was created with 74.5% females. Whilst it is now recognised that social camouflaging transcends sex/gender, there is still an overall increased propensity for females to camouflage (Lai et al., 2017; 2019; Jorgenson et al., 2020). It is strongly recommended that the

available methods recruit samples that can facilitate potential between sex/gender differences in the reporting of camouflaging behaviour.

Missing information from current methodologies

Many different methods of assessing camouflaging are now available, however, researchers have not yet sought to investigate their applicability across different cultures. The available research was mainly completed within the UK, with some also occurring within the United States, Australia, and Poland. Given that camouflaging can be thought of as arising due to a complex interaction between the autistic individual and their environment (Cage & Troxell-Whitman, 2019), it is possible that camouflaging may take different forms across different cultures. It may also change across different genders and age groups, depending upon the perceived necessity to appear neurotypical. Future camouflaging research should consider this, making adjustments to the measurement tools as necessary.

None of the available methodologies investigated the possibility of responsiveness of their measure; that is, changing camouflaging scores in response to true changes in camouflaging behaviour. Whilst this would be advantageous, it should be acknowledged that many of the camouflaging measures placed a different emphasis on when camouflaging takes place. For example, observational methods of camouflaging were concerned with potential camouflaging within an allotted time period in front of the examiner. This focus on camouflaging in front of an examiner is also the primary focus of discrepancy methods. Comparatively, many questionnaires considered the historical nature of, attitudes towards, and intention to camouflage. As such, many of the questionnaire measures may require changes and revalidation in order to specify time periods of interest to enable measurement

responsiveness to be assessed. The importance of including measurement responsiveness is, however, a matter for future consideration as clinicians may consider intervening with camouflaging, in light of its link with poor mental health outcomes (Boyd et al., 2011; Cassidy et al., 2018; Lai et al., 2011; Simone, 2010; Willey, 1999; Williams, 1992).

Interpretation of camouflaging measures and clinical use

Much of the justification for conducting camouflaging research is the potential for its incorporation into clinical work, in the hope that this may reduce missed, or misdiagnosis, particularly for autistic females. Whilst this would undoubtedly be helpful, the lack of a robust measurement tool, highlighted by the COSMIN, demonstrates that this is still a distant endeavour. The current lack of information on reliability of measurement for nearly all measures highlights the need for further research before any measurement tool can assist clinically.

The interpretability of each measurement tool should also be considered before any may be incorporated into clinical practice. Many of the current discrepancy methods demonstrated camouflaging based upon centralising the data from their current study, or using median splits within their sample. Meaningful scores for individuals attending an assessment clinic are therefore not available. Discrepancy measurement authors may now wish to provide further information as to the potential translatability into clinical practice, and the minimum discrepancy score that may impact diagnosis. Contrastingly, many of the observational and reflective tools provided a quantitative camouflaging score. However, how such a score is interpreted on its own is not immediately obvious. As such, it would be beneficial for future research to consider whether there is a critical camouflaging

score, or potentially provide normal data, which can be incorporated into a clinical assessment, in order to avoid potential missed or misdiagnosis.

Current taxonomy of available methods

As previously mentioned (c.f. p. 17), Hull, Mandy et al. (2019) provide their taxonomy of available methodologies in the measurement of camouflaging; however, this could now be further refined. Segregating questionnaire and observational approaches is now recommended. Whilst it is possible to investigate each methodology in terms of their validity and reliability, as demonstrated in the above review, the components of these properties do not perfectly overlap. For example, all questionnaire methods can be evaluated by their structural validity, but this is not possible for any observational method. As the current review was not seeking to compare across measures, but instead consider the current evidence for the available measures, comparison was not an issue. However, future research may wish to compare measures. As such, it is imperative that each measure can be compared to the same standard.

In addition, how camouflaging is measured within these methodologies is starkly contrasting, with different aspects of such behaviour likely being measured. Questionnaire methods are exclusively reliant upon reflection of previous thoughts or behaviours, enabling both successful and unsuccessful camouflaging attempts to be scored, but potentially missing unconscious camouflaging attempts. Such methods may therefore be best placed to measure intention and/or conscious awareness of camouflaging behaviour. Observational methods are exclusively reliant upon camouflaging whilst a researcher/clinician is present, enabling successful unconscious camouflaging to be captured, but unsuccessful camouflaging attempts to

potentially be missed. Conversely, discrepancy measures focus exclusively upon camouflaging performance. They are therefore best placed to assess the degree to which an individual is successful at camouflaging their autistic traits. As such, camouflaging research may wish to consider discrepancy, observational, and questionnaire methods as three complementary approaches, with the possibility of measuring camouflaging intention/awareness (questionnaire), successful unconscious camouflaging (observation), and camouflaging performance (discrepancy). Future research should now seek to incorporate each of these complimentary approaches in order to improve our knowledge of social camouflaging.

Limitations

Whilst this review is the first of its kind to appraise the current methodologies of assessing the camouflaging of autistic behaviours, it is not without its limitations. Firstly, it should be acknowledged that the COSMIN is designed to measure health related patient reported outcomes. Whilst this may suggest that the tool is biased towards the reporting camouflaging through questionnaire measures, it should be noted that the staple characteristics of psychometric quality, such as reliability and validity, translate across all measures. Moreover, where it was not possible to fully appraise a methodology on a domain because it is not applicable, this can be left as non-assessable without punishing the measure on an overall score/metric (e.g. internal consistency for both discrepancy and observational data). Given the popularity of the COSMIN checklist as a psychometric assessment instrument (for review, see Rosenkoetter & Tate, 2018), and its flexibility in evaluating constituent psychometric components, its incorporation into a novel research area is valuable,

particularly when evaluating discrepancy methods, where no specific psychometric standards have been set.

In addition, it should be noted that the COSMIN defines structural validity as an adequate reflection of the dimensionality of the construct. Whilst high ratings were possible as long as factor analysis was completed, it does not take into account the necessity of construct validity in reflecting the dimensionality of the construct. As such, it is possible for tools to receive high structural validity scores on the COSMIN without adequate representation of the construct being measured. Without the latter, the former appears meaningless. Given that camouflaging is a novel area of research, it is possible that the COSMIN does not adequately consider the necessity of both of these areas working in tandem when appraising their psychometric qualities.

The COSMIN checklist is also limited in its definition of measurement error. When calculating a standard error of measurement statistic, it is possible to use either the internal consistency or test-retest statistic as a measure of reliability (see Leong & Huang, 2010). However, as the COSMIN necessitates a rating of 'poor' in the absence of two separate administrations of the measurement tool, it implies that measurement error is not calculable without test-retest data. Future users of the COSMIN checklist may wish to consider this when appraising measurement error.

Finally, the current review limited its searches to four terms associated with camouflaging. Given that camouflaging is a relatively new area of research, it is possible that other terms are being used to describe the same phenomena without the author's awareness. Future research may wish to continue to search for and understand, along with the autistic community, other words and phrases that have been used to describe camouflaging.

Conclusion

Camouflaging research has exploded in popularity, particularly within the last five years. Of the thirteen papers included in the current review, none were published prior to 2016. Research questions have started to move beyond the studying of camouflaging itself, and are asking about motivations and outcomes of camouflaging behaviour. However, the current review highlights how the available measures of camouflaging are yet to demonstrate the necessary psychometric validity and reliability to provide confident and replicable outcomes. As such, researchers in this area should consider further refinement of the tools as a high priority. Moreover, how such tools could be integrated within clinical practice should be considered. Without answers to such questions, potential missed and misdiagnosis of autistic individuals may well persist.

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Part 2: Empirical Paper

The role of VIQ in the camouflaging of autistic traits.

Abstract

Aims: Camouflaging autistic traits during social interactions is thought to draw upon high-level cognitive abilities. However, there is little information about which cognitive abilities may facilitate such camouflaging. One potential candidate is verbal intelligence. As such, the current research investigated whether verbal intelligence quotient (VIQ) could predict camouflaging behaviour.

Methods: A total of 59 adolescents, aged between 13-17, completed a battery of cognitive and behavioural tasks. Adolescents and parents also completed a series of questionnaires. Three distinct, but related metrics of camouflaging behaviour were calculated. This included a mathematical discrepancy between observer and self-rated autistic status, self-rated camouflaging scores, and parent-rated camouflaging scores. Performance on a short measure of intelligence was used to assess whether VIQ could predict scores on each of these three camouflaging metrics, after controlling for executive functioning and autistic-like traits.

Results: Verbal intelligence quotient was able to significantly predict scores on a camouflaging discrepancy measure, and scores on a parent-rated camouflaging questionnaire. However, VIQ was not a significant predictor of self-rated camouflaging.

Conclusions: The current results suggest that VIQ is important for successfully camouflaging autistic traits, but appears less influential when someone intends to

camouflage. These findings should now be used by clinicians and primary care providers to reduce the possibility of missed or misdiagnosis.

Introduction

Autism Spectrum Disorder (ASD; hereafter 'autism') refers to a cluster of neurodevelopmental conditions characterised by struggles with social communication, sensory processing, and flexibility (APA, 2013). Autism is one of the most common neurodevelopmental difficulties, with an estimated prevalence between .6 – 1.5% (Brugha et al., 2011; Fombonne, 2005; 2009; Lyall et al., 2017). Whilst clinicians have become better at diagnosing autism, many individuals are still missed (Aggarwal & Angus, 2015). There has been a growing interest in the idea that social camouflaging might partly explain this (Lai & Baron-Cohen, 2015).

Social camouflaging is the combination of masking and compensatory techniques used by autistic people, that can occur both consciously and unconsciously, when attempting to conceal their autistic traits within a social situation (Lai et al., 2011). Masking can involve the presentation of a non-autistic character to others, or the concealment of stereotypically autistic characteristics, such as self-stimulatory behaviour or 'stimming'. Conversely, compensation refers to more active techniques to circumvent social and communication difficulties associated with autism; for example, by forcing eye contact or creating scripts for conversation. Whilst the concept of social camouflaging may partially overlap with impression management (see Goffman, 1959), its prevalence is positively associated with autistic traits (Hull et al., 2019), highlighting a specific relationship between camouflaging and autism.

Despite the growing interest, it should be emphasised that not all autistic individuals camouflage. Camouflaging behaviour shows high variability across individuals, with some engaging in such behaviour more than others (Lai et al.,

2017). For those that do camouflage, this does not occur consistently across place and time. The motivation to do so is likely dependent upon a complex interplay between the situation and context, for example, who else is present (e.g. friend vs colleague), and what the objective of camouflaging is (Cage & Troxell-Whitman, 2019). Some common motivating factors for camouflaging have included increased job opportunities, social connections, and reciprocal comfort during social interactions (Hull et al., 2017). Despite these motivating factors, it is currently unclear to what extent camouflaging is successful in achieving these goals.

Interest in social camouflaging was born out of the known discrepancy in diagnosis between males and females, but has since evolved. Historically, male-to-female ratios of autism have likely been overstated. Current estimates are quoted as somewhere between 4:1 or 3:1 (Fombonne, 2009; for review, see Loomes, Hull & Mandy, 2017). Whilst this sex/gender¹ disparity has traditionally held true within the ‘higher functioning’ end of autism, diagnostic discrepancies often reduce as functioning decreases (Bryson, Clark & Smith, 1988; Yeargin-Allsopp et al., 2003). One possible explanation for this was the increased prevalence of social camouflaging strategies used by higher functioning autistic females, causing many to either be missed, or misdiagnosed (Dworzynski, Ronald, Bolton & Happé, 2012; Lai & Baron-Cohen, 2015; Kopp & Gillberg, 1992). Whilst at the group level it is possible to see greater camouflaging in females (Hull et al., 2019; Schuck, Flores & Fung, 2019), the variability of camouflaging behaviour within both males and females is large (Lai et al., 2017). Moreover, both men and women are equally likely to spontaneously report camouflaging behaviour (Cage, Di Monaco & Newell, 2017). As such, whilst camouflaging may be more common in females, potentially due to factors such as societal stigma for not conforming to the male stereotype of

¹The current paper uses the term sex/gender to recognise that it is difficult to disentangle group differences that are driven by biological sex differences compared to culturally driven gender differences.

autism, or norms for conventional females behaviour (Cage & Troxell-Whitman, 2019), it can occur across the whole autistic community, regardless of sex/gender.

Increasing our knowledge of social camouflaging is now vital, given its known relationship with poor mental health outcomes. Qualitatively, autistic individuals have described feeling as if they fall to pieces or are not their true self when engaging in camouflaging behaviour (Hull et al., 2017). Quantitatively, increased camouflaging has been linked with depression, anxiety, and reduced general wellbeing (Bargiela, Steward & Mandy, 2016; Hull et al., 2019; Lai et al., 2017). It has also been found to predict suicidality in autistic adults (Cassidy, Bradley, Shaw & Baron-Cohen, 2018). As such, adequately understanding and recognising social camouflaging may not only place clinicians in a better position to accurately diagnose autism, but also potentially provide access to timely support in the hope of improving mental health prognosis. Increasing our knowledge of camouflaging could also inform families, teachers, or primary care providers, who are often the first people to trigger the necessary channels for autism assessment.

One way to improve our knowledge, and recognition of social camouflaging, is by understanding the cognitive mechanisms that support camouflaging behaviour. Camouflaging is thought to draw upon high-level cognitive abilities, given that it is a complex social-cognitive process (Cassidy et al., 2018). An individual must first understand their social difficulties, how these may be negatively evaluated by others, and be motivated to change their behaviour to increase the likelihood of social acceptance (Cassidy et al., 2018). Simultaneously, the person must sensitively monitor their environment and choose appropriate response strategies (Lai et al., 2017). By increasing our knowledge of what cognitive abilities support camouflaging, and assessing these appropriately, clinicians may be better placed to

help identify those who are at risk of camouflaging during diagnostic assessments, and subsequently falling short of diagnostic cut offs. In addition, increased understanding of such cognitive abilities could help improve the validity of current and future camouflaging measurement tools, which could in turn could also improve diagnostic accuracy. Finally, understanding these cognitive mechanisms could allow clinicians to proactively identify individuals who are likely to attempt camouflaging behaviour in the future, and potentially intervene to reduce the risk of poor mental health outcomes. Further research into this area is therefore timely and necessary.

Knowledge about the potential cognitive abilities that underpin camouflaging behaviour is limited, however, increased executive functioning appears to play a role. Adolescents who were rated as highly compensating for their autistic traits scored higher on a battery of executive functioning tasks, when compared to low compensators (Livingston, Colvert, SRST, Bolton, & Happé, 2019). Additional research has also indicated a linear relationship between camouflaging behaviour and increased response inhibition (Lai et al., 2017). Whilst executive functioning appears implicated, given the complexity of the camouflaging process, it is unlikely to be a single explanatory cognitive mechanism that underpins such behaviour.

A further cognitive ability that may support social camouflaging is verbal intelligence. Verbal intelligence quotient (VIQ) is a measure of acquired verbal knowledge and verbal reasoning skills (Lange, 2011). Whilst VIQ has often been considered part of a broad two-factor solution of intelligence, along with Non-Verbal IQ (NVIQ), the two are distinguishable. Performance *within* VIQ subtests have consistently been found to highly correlate, whilst subtest performance *across* VIQ and NVIQ subtests demonstrate much lower levels of association (see Mackintosh & Mackintosh, 2011). VIQ has been repeatedly linked with social ability and external

autistic presentation. Specifically, prior research has highlighted a linear trend between increased VIQ and improved social functioning for autistic females (Skuse et al., 2009). When assessed using the Autism Diagnostic Observation Schedule (ADOS), school aged autistic children with equal or greater VIQ compared to NVIQ display fewer social symptoms of autism (Joseph, Tager-Flusberg & Lord, 2002). Moreover, VIQ has been found to positively correlate with adaptive communication (Klin et al., 2007). As such, it is possible that VIQ may influence external autistic presentation.

Preliminary research into the possible relationship between VIQ and social camouflaging has already taken place. This was first investigated using a mathematical discrepancy between internal autistic traits (measured by the Autism-Spectrum Quotient questionnaire; Baron-Cohen, Wheelwright, Skinner, Martin & Clubley, 2001) and external autistic traits (measured by the ADOS; Lord et al., 2000), with this numerical gap thought to represent camouflaging (Lai et al., 2017). The authors demonstrated a medium effect size correlation between VIQ and camouflaging that did not reach statistical significance, possibly due to the study being underpowered. However, it should be noted that the use of a discrepancy method has its limitations. This technique is only able to assess ‘successful’ camouflaging in front of the assessing clinician or researcher. As such, unsuccessful camouflaging attempts can be missed (Hull, Petrides & Mandy, 2020). Moreover, at present, measures of internal autistic traits are reliant upon an index of how ‘truly autistic’ an individual is. Given that autism is a behavioural diagnosis with no reliable biomarkers, there is no possibility of measuring ‘true’ autism. As such, further investigation into VIQs potential association with social camouflaging, using

more than one measurement tool, could provide greater understanding of this relationship.

The recent increase in camouflaging research has now led to a taxonomy of different measurement methodologies (Hull et al., 2020). As well as the previously mentioned discrepancy methods, observational/reflective methods are also available. Observational/reflective methods measure camouflaging either from the point of view of an observer, or through self-reflection (Hull et al., 2020). One such technique is the Camouflaging of Autistic Traits Questionnaire (CAT-Q; Hull et al., 2019), which requires participants to report previous camouflaging, and camouflaging intentions, across all contexts. As such, individuals who may have previously scored relatively low on discrepancy methods, potentially due to low camouflaging success, or low motivation to attempt camouflaging behaviour, can provide further information about their intent to camouflage. It should however be noted that higher scores on questionnaires such as the CAT-Q are associated with greater autistic-like traits. As such, greater camouflaging scores may reflect more autistic behaviours to be camouflaged for (Hull et al., 2019).

At present, there is no recognised ‘gold standard’ of camouflaging measurement tools, with discrepancy and observational/reflective methods appearing to measure different aspects of social camouflaging. The available discrepancy methods hold significant strengths in terms of their ability to measure and quantify the concealment of autistic traits in front of an assessing researcher or clinician (i.e. successfully camouflaged autistic traits). Comparatively, observational/reflective methods enable participants to report upon their intention to camouflage across all contexts, regardless of whether this camouflaging behaviour successfully conceals

autistic traits from an observer. As such, current research into social camouflaging may benefit from utilising both of these measurement types.

Current research

Further investigation into the possibility of VIQ being associated with social camouflaging is now required. In order to reduce reliance upon an individual measurement tool and to investigate different elements of camouflaging (e.g. success vs. intent), the current research utilised three different measures, including a discrepancy method (akin to Lai et al., 2017), a self-report questionnaire (CAT-Q; Hull et al., 2019), and a novel parent report measure (CAT-Q parent; Hull, 2020).

Whilst VIQ appears an obvious candidate as a cognitive ability that underpins camouflaging behaviour, it is unlikely to be a single explanatory variable. Executive functioning ability has previously been linked with camouflaging behaviour (Lai et al., 2017; Livingston et al., 2019), whilst the number of autistic-like traits have also been suggested to increase scores on camouflaging measures (Hull et al. 2019). As such, in order to investigate the unique explanatory power of VIQ in camouflaging, executive functioning and autistic like-traits will also be assessed and controlled for throughout the research.

Beyond the main analysis, further exploratory research using the current data will be completed. Prior research with autistic school children has demonstrated a protective role for VIQ against social communication difficulties that is more evident in females compared to males (Skuse et al., 2009). When combined with the known sex/gender differences in camouflaging behaviour (c.f. p.65), it is possible that any relationship between VIQ and camouflaging may differentiate by sex. As such,

exploratory research will be conducted to assess whether the main findings persist after segregating sex/gender.

In summary, the current research will attempt to answer the following questions:

- Is VIQ positively associated with camouflaging as measured by a discrepancy method after controlling for executive functioning and autistic-like traits?
- Is VIQ positively associated with camouflaging as rated by parents after controlling for executive functioning and autistic-like traits?
- Is VIQ positively associated with self-rated camouflaging after controlling for executive functioning and autistic-like traits?
- Does this potential relationship continue after segregating sex/gender?

Method

Ethics

The study received Health Research Authority and Research Ethics Committee (REC Number: 17/LO/2055) approval in December 2017 (Appendix B; note that this approval was related to an amendment for a larger research project).

Participants

Sample size

Prior research from Lai et al. (2017) indicated a medium effect size correlation between VIQ and camouflaging. As such, utilisation of the programme G*Power (Faul, Erdfelder, Lang & Buchner, 2007) indicated that to achieve a similar effect

size for multiple regression analysis with three predictors, 80% power, and .05 alpha, 77 participants were required.

Recruitment

Participants aged between 13 and 19 years old were eligible to take part in the research. Recruitment took place via social media, word-of-mouth, and through NHS based clinics (Appendix C). All participants were required to have a confirmed diagnosis of an ASD from a qualified clinician (including autism, Asperger Syndrome, high functioning autism, pervasive developmental disorder), and speak fluent English. Participants with a self-diagnosis of autism were excluded. Due to the limited research and information about social camouflaging in autistic individuals with a recorded intellectual disability, participants who obtained a Full-Scale IQ lower than 70 on the subsequent testing procedure, or those with a previously recorded intellectual disability were excluded.

Fifty-nine autistic adolescents took part in the study. Following the testing procedure, one participant obtained a full-scale IQ lower than 70. As such, their data was excluded from subsequent analysis, leaving fifty-eight participants in the final sample, including 29 males and 29 females. Participants' ages ranged from 13-17 years-old ($M = 14.31$, $SD = 1.34$). All participants were entered into a prize draw for high street vouchers in return for participation.

Materials

Wechsler Abbreviated Scale of Intelligence

Intellectual ability was assessed using the Wechsler Abbreviated Scale of Intelligence, second edition (WASI-II; Wechsler, 1999). The WASI-II is a

standardised brief measure of intelligence for both children and adults from 6-90 years old. Four subtests were administered: block design, vocabulary, matrix reasoning, and similarities. These provide estimates of a participants' full-scale IQ (FSIQ), NVIQ and VIQ. For the current research, all scores from the WASI-II were analysed using the associated composite scores ($M = 100$, $SD = 15$), with higher scores indicating greater intellectual ability. The WASI-II has previously demonstrated high levels of test-retest reliability in both children ($r = .96$) and adults ($r = .97$) (Maccow, 2011).

Autism Diagnostic Observation Schedule

To calculate external autistic status for the subsequent discrepancy measure of social camouflaging, the Autism Diagnostic Observation Schedule, module four (ADOS; Lord et al., 2000) was used. The ADOS is an interview-based assessment that measures the behavioural presentation of autistic characteristics in a semi-structured setting. In line with Lai et al. (2019), the current analysis used the Social Affect domain score from the updated algorithm (Hus & Lord, 2014). This ranges from zero to 10, with higher scores indicative of greater autistic symptomology. Module four of the ADOS has previously been found to have adequate discriminative validity (Bastiaansen et al., 2011) and good interrater reliability ($\kappa \geq .60$ for most items; Hus & Lord, 2014). The Social Affect domain score has also previously demonstrated good internal consistency ($\alpha = .84$; Hus & Lord, 2014).

Autism-Spectrum Quotient

For the discrepancy measure of social camouflaging, internal autistic status was assessed using the Autism-Spectrum Quotient (AQ). The AQ is a self-report

questionnaire that assesses autistic-like traits across areas such as social skills, communication, and imagination (Baron-Cohen et al., 2001). It contains 50 items, with four possible responses ranging from ‘definitely agree’ and ‘slightly agree’, to ‘slightly disagree’ and ‘definitely disagree’. Example items include “I am fascinated by dates” and “I tend to have very strong interests, which I get upset about if I can’t pursue”. Responses that endorse an autistic characteristic (i.e. either definitely or slightly) receive a score of one, whilst non-endorsed responses receive a score of zero. Items can be summed to create a total AQ score, with higher scores indicating greater autistic-like traits. In the current study, the AQ demonstrated good internal consistency ($\alpha = .86$). The AQ has also been previously found to have good test-retest reliability ($r = .70$; Baron-Cohen et al. 2001) and discriminative validity (Woodbury-Smith, Robinson, Wheelwright & Baron-Cohen, 2005).

Camouflaging of Autistic Traits Questionnaire

Self-reported camouflaging was assessed using the Camouflaging of Autistic Traits Questionnaire (CAT-Q; Hull et al., 2019). The CAT-Q is a 25-item self-report questionnaire investigating camouflaging behaviour during social interactions. Each item requires a response across a seven-point Likert-scale, ranging from ‘strongly disagree’ to ‘strongly agree’. Example items include “I rarely feel the need to put on an act in order to get through a social situation” and “in social situations, I feel like I am pretending to be ‘normal’”. Summation of responses provides an overall camouflaging score, with higher scores indicating greater camouflaging. If items were incomplete, the CAT-Q was excluded from analysis. In the current study, the self-report CAT-Q demonstrated excellent internal consistency ($\alpha = .91$). Prior

research has also demonstrated acceptable test-retest reliability for the CAT-Q (Hull et al., 2019).

Parent Camouflaging of Autistic Traits Questionnaire

The Parent Camouflaging of Autistic Traits Questionnaire (P-CAT-Q; Hull, 2020) was used as a measure of parent rated camouflaging. The P-CAT-Q is a new questionnaire based upon the self-report CAT-Q, however, wording has been changed to reflect parental observations, e.g. “in social situations I feel like I’m ‘performing’ rather than being myself” becomes “in social situations, my child is ‘performing’ rather than being themselves.”. Summation of responses provides an overall camouflaging score, with higher scores indicating greater camouflaging. If items were incomplete, the P-CAT-Q was excluded from analysis. In the current study, the P-CAT-Q demonstrated excellent internal consistency ($\alpha = .91$).

Behavioural Rating Inventory of Executive Functioning - Parent

To help understand the unique explanatory variance in social camouflaging by VIQ, executive functioning was assessed using the Behavioural Rating Inventory of Executive Functioning, second edition, parent report (BRIEF-2; Gioia, Isquith, Guy & Kenworth, 2000). The BRIEF-2 (parent) is an 86-item parent completed questionnaire for children from 5-18 years old. Parents respond to statements across a three-point scale, including ‘never’, ‘sometimes’, and ‘often’. Example items include “has explosive, angry, outbursts” and “has a short attention span”. The BRIEF provides a scaled T score ($M = 50$, $SD = 10$), with higher scores indicating greater executive difficulties. The questionnaire provides three subscales including: behaviour regulation index, emotion regulation index, and cognitive regulation

index. It is also possible to calculate a cognitive regulation index, and global executive composite. Due to the current literature holding little information about which specific executive functions may relate to camouflaging behaviour, and to reduce the likelihood of inflating type one error, the global executive composite was used in the current study. Prior research has indicated that the BRIEF-2 (parent) has good internal consistency ($\alpha = >.80$) and test-retest reliability ($r = .79 - .81$) in both clinical and non-clinical samples (Gioia et al., 2000).

Social Responsiveness Scale

In order to control for the possibility of greater camouflaging scores reflecting more autistic behaviours to be camouflaged for, the Social Responsiveness Scale (SRS) (Constantino & Gruber, 2007) was used. The SRS is a parent completed, 65-item questionnaire that measures autistic-like traits. The items focus upon aspects of reciprocal social behaviour that are known to be associated with autism. Participants respond to statements along a four-point Likert-scale, ranging from ‘never true’ to ‘almost always true’. Example items include “when under stress, he or she shows rigid or inflexible patterns of behaviour that seem odd” and “can’t get his or her mind off something once he or she starts thinking about it”. The SRS provides a scaled T score ($M = 50$, $SD = 10$) to refer to the severity of social difficulties. Higher scores are indicative of greater autistic-like traits. Prior research has demonstrated that the SRS has excellent internal consistency ($\alpha = .92$; Wigham, McConachie, Tandos, Le Couteur & GMSCT, 2012), good interrater ($r = .75 - .91$) and test-retest reliability ($r = .83$; Constantino et al., 2003).

Procedure

Prior to the agreed test date, all parents and young people were provided with a detailed study description (Appendix D). All data collection took place in the participant's homes, University College London (UCL) testing rooms, or the participant's school, depending upon personal preference. Travel expenses up to £10 per adult and £5 per child were offered for participants travelling to the UCL testing rooms. All testing was completed by doctoral students collaborating on a larger research project into social camouflaging and autism (see Chapman, 2020; Hull, 2019; Appendix E). One doctoral student administered all tests individually on the agreed testing date. The current author completed testing with 14 participants.

Upon study commencement, all participants were informed of their right to withdraw and asked to sign assent forms (children under 16) and/or consent forms (parents of children under 16, or children over 16) (Appendix F). Parents were subsequently asked to complete the P-CAT-Q, BRIEF-2 and SRS. Although not used in the current research, as part of the larger research project, parents were also required to complete the Strengths and Difficulties Questionnaire (SDQ; Goodman, Meltzer & Bailey, 1998). All children began by completing the ADOS module 4, followed by the WASI-II. They subsequently completed a battery of questionnaires including the AQ and CAT-Q. As part of the larger research project, each young person was also required to complete the Friendship Questionnaire (Baron-Cohen & Wheelwright, 2003), SDQ (Goodman et al., 1998), Strange Stories Task (Happé, 1994) and a newly developed Social Impressions task (based upon Sasson et al., 2017). All participants were provided with the opportunity for breaks between tasks. Data collection took approximately two and a half hours, including breaks. All participants were debriefed and provided the opportunity to ask questions.

Data analysis

Scoring for each measure was completed by the researcher undertaking the assessment. Each ADOS was scored immediately after the session was completed. All researchers were provided with ADOS training by the same certified ADOS trainer. To ensure consistency when scoring the ADOS, the research team attended three calibration meetings, scoring previously recorded data from the current project. Differences in scoring were discussed until consensus was reached. All administrations of the ADOS were recorded to facilitate double coding, as needed.

Discrepancy Camouflaging Score

Similar to Lai et al. (2017; 2019) and Schuck et al. (2019), the discrepancy camouflaging measure used in the current analysis was created by quantifying the difference between internal and external autistic status. Internal autistic status was calculated using the AQ, whilst external autistic status was operationalised using the Social Affect domain score from the ADOS. First, both scores were mean centred (using the current sample) and scaled by dividing by the maximum possible score for each measure. This enabled the creation of an S_{AQ} and S_{ADOS} score. Camouflaging scores (CF) were then created by subtracting S_{ADOS} from S_{AQ} . Higher scores were interpreted as indicative of increased camouflaging.

Regression Analysis

In order to look at the purest relationship between VIQ and social camouflaging, a series of hierarchical regression models were conducted using the three available camouflaging measures (CF, CAT-Q & P-CAT-Q) as outcome variables. For all

analyses, both executive functioning and autistic-like traits were included in model one, and VIQ added at model two, to enable the unique contribution of VIQ to be seen using the R^2 change statistic. Due to the known, but distinct relationship between executive function and VIQ (Ardila, Pineda & Rosselli, 2000; Arffa, 2007), and the known relationship between autistic traits and VIQ (Black, Wallace, Sokoloff & Kenworthy, 2009), these variables were included in all analyses to avoid potential suppressor effects (see Pandey & Elliott, 2010 for review of suppression effects in linear regression). All data analysis was performed in SPSS version 26 (IBM, 2019). Data was treated as interval, using an alpha level of .05 (two tailed).

Results

Preliminary assumption testing indicated that all assumptions (linearity, normal distribution, and no significant outliers) for correlation analysis were met.

Assumption tests for subsequent multiple regression analysis (independence of residuals, homoscedasticity, normal distribution of residuals, and no perfect multicollinearity or significant outliers) were also met, unless otherwise stated.

Key participant characteristics and scores are described below in table one.

Table 1

Sample characteristics and scores on the current measures

	Minimum	Maximum	Mean (SD)
Age in years	13	17	14.31 (1.34)
WASI FSIQ	71	130	103.38 (14.69)
NVIQ	68	139	105.17 (15.74)
VIQ	72	132	99.64 (14.25)
ADOS Calibrated Total Severity Score	0	10	5.68 (2.81)
ADOS Calibrated Total Social Affect Score	0	10	5.84 (2.61)
ADOS Calibrated Total RRB Score	0	10	5.20 (3.01)
Total AQ Score	7	45	25.98 (8.40)
CF	-.60	.46	-.001 (.25)
CAT-Q	62	169	103.98 (25.95)
P-CAT-Q	56	164	106.31 (23.32)
BRIEF-2 Parent General Executive Component	41	90	72.36 (10.73)
SRS Total T Score	46	90	79.23 (10.07)

WASI FSIQ: Wechsler Abbreviated Scale of Intelligence – Full Scale Intelligence Quotient; NVIQ: Non-Verbal Intelligence Quotient; VIQ: Verbal Intelligence Quotient; ADOS: Autism Diagnostic Observation Schedule; RRB: Restrictive and Repetitive Behaviours; AQ: Autism-Spectrum Quotient; CF: Discrepancy Camouflaging Scores; CAT-Q: Camouflaging of Autistic Traits Questionnaire; P-CAT-Q: Parent-report Camouflaging of Autistic Traits Questionnaire. BRIEF-2: Behavioural Rating Inventory of Executive Function – 2nd Edition; SRS: Social Responsiveness Scale.

Preliminary correlations

In order to view the relationship between the three measures of camouflaging and VIQ, a series of Pearson’s correlations were conducted (see table 2, below for correlation matrix). Of note, the results indicated a significant correlation between a participants’ VIQ and CF score, $r = .35, p = .035$. However, VIQ did not correlate with self-reported camouflaging (CAT-Q), $r = .24, p = .121$; nor did it correlate with parent reported camouflaging (P-CAT-Q), $r = .25, p = .101$. Neither NVIQ or FSIQ significantly correlated with CF, self-rated, or parent-rated camouflaging. The current results also demonstrated significant intercorrelations between the three camouflaging measures, with CF significantly correlating with both CAT-Q ($r = .31, p = .045$) and P-CAT-Q ($r = .41, p = .006$). In addition, CAT-Q and P-CAT-Q also significantly correlated ($r = .56, p < .001$).

Table 2

Correlation matrix with camouflaging variables and predictor variables

	CF	CAT-Q	P-CAT-Q	FSIQ	VIQ	NVIQ	BRIEF-2	SRS
CF								
CAT-Q	.31*							
P-CAT-Q	.41**	.56**						
FSIQ	.26	.09	.21					
VIQ	.35*	.24	.25	.87**				
NVIQ	.08	-.08	.14	.88**	.55**			
BRIEF-2	-.06	-.28	-.20	-.29*	-.18	-.26		
SRS	.15	-.06	.02	-.32*	-.26*	-.22	.53**	

* Correlation is significant at .05

** Correlation is significant at .01

CF: Discrepancy Camouflaging Scores; CAT-Q: Camouflaging of Autistic Traits Questionnaire; ; P-CAT-Q: Parent-report Camouflaging of Autistic Traits Questionnaire. FSIQ: Full Scale Intelligence Quotient; VIQ: Verbal Intelligence Quotient; NVIQ: Non-Verbal Intelligence Quotient; BRIEF-2: Behavioural Rating Inventory of Executive Function – 2nd Edition; SRS: Social Responsiveness Scale.

Is VIQ positively associated with camouflaging as measured by a discrepancy method after controlling for executive functioning and autistic-like traits?

Whilst the above results suggest a significant relationship between VIQ and CF, further analysis was conducted to assess if VIQ is related to CF, after taking into account the variance explained by executive functioning and autistic-like traits. Of the original 58 participants, 41 had complete CF, VIQ, BRIEF-2, and SRS measures. For the first step of the hierarchical regression, BRIEF-2 and SRS scores were entered into the model. The results indicated that the model did not significantly predict CF scores ($F(2, 38) = .97, p = .387$), and accounted for approximately 5% of the variance ($R^2 = .049$). The second step added VIQ to the regression model. Results indicated that the model significantly predicted CF scores ($F(3, 37) = 2.92, p = .047$), accounting for approximately 19% of the variance ($R^2 = .191, R^{2A} = .143$). Table three (below) reports the standardised (β) and unstandardised (B) regression coefficients for model one and model two. For model two, only VIQ was a significant predictor of CF scores ($\beta = .40, t(37) = 2.55, p = .016$).

Table 3

Standardised and unstandardized beta coefficients for model one and two when predicting camouflaging discrepancy score

	B	95% CI B	β	<i>t</i>	<i>p</i>
Model 1					
BRIEF-2	-.004	-.013 - .006	-.145	.77	.446
SRS	.007	-.003 - .017	.263	1.40	.171
Model 2					
BRIEF-2	-.002	-.011 - .007	-.086	.48	.632
SRS	.009	-.001 - .019	.341	1.91	.064
VIQ	.007	.001 - .013	.397	2.55	.015

BRIEF-2: Behavioural Rating Inventory of Executive Function – 2nd Edition; SRS: Social Responsiveness Scale; VIQ: Verbal Intelligence Quotient.

Is VIQ positively associated with camouflaging as rated by parents after controlling for executive functioning and autistic-like traits?

Whilst there was no significant correlation between VIQ and P-CAT-Q, hierarchical linear regression was used to assess a potential relationship after controlling for executive functioning and autistic traits. Of the original 58 participants, 42 had complete P-CAT-Q, VIQ, BRIEF-2 and SRS measures. Scores from the BRIEF-2 and SRS were entered into model one. The results indicated that the model did not significantly predict P-CAT-Q scores ($F(2, 39) = 1.35, p = .271$), with the combination of BRIEF-2 and SRS scores accounting for approximately 7% of the variance ($R^2 = .065$). The second step of the regression model added VIQ to the analysis. The results indicated a non-significant trend in the overall model's ability to predict P-CAT-Q scores ($F(3, 38) = 2.45, p = .078$), accounting for approximately 16% of the variance ($R^2 = .162$). Adding VIQ to the model significantly improved its predictive value ($F(1, 38) = 4.42, p = .042, R^{2\Delta} = .097$). Table four (below) reports the standardised (β) and unstandardised (B) regression coefficients for model one and model two. For model two, only VIQ was a significant predictor of P-CAT-Q scores ($\beta = .319, t(38) = 2.10, p = .042$).

Table 4

Standardised and unstandardized beta coefficients for model one and two when predicting parent rated camouflaging

	B	95% CI B	β	<i>t</i>	<i>p</i>
Model 1					
BRIEF-2	-.673	-1.501 – 1.55	-.301	1.64	.108
SRS	.377	-.518 - 1.271	.156	.85	.399
Model 2					
BRIEF-2	-.608	-1.405 - .189	-.272	1.54	.131
SRS	.479	-.384 – 1.343	.199	1.12	.268
VIQ	.545	.020 – 1.069	.319	2.10	.042

BRIEF-2: Behavioural Rating Inventory of Executive Function – 2nd Edition; SRS: Social Responsiveness Scale; VIQ: Verbal Intelligence Quotient.

Is VIQ positively associated with self-rated camouflaging after controlling for executive functioning and autistic-like traits?

To further understand if there is a relationship between VIQ and CAT-Q scores after controlling for executive functioning and autistic-like traits, hierarchical regression was used. Of the original 58 participants, 41 had complete CAT-Q, VIQ, BRIEF-2 and SRS measures. The first step of the regression model included BRIEF-2 and SRS scores. The results of this first step indicated that the model significantly predicted CAT-Q scores ($F(2, 38) = 4.17, p = .023$). When combined, BRIEF-2 and SRS scores were found to predict approximately 18% of the variance in CAT-Q scores ($R^2 = .180$). The second step of the model included VIQ. The results indicated that the model continued to significantly predict CAT-Q scores ($F(3, 37) = 3.17, p = .035$), accounting for approximately 21% of the variance ($R^2 = .205$). However, adding VIQ to the model did not significantly improve its predictive value ($F(1, 37) = 1.16, p = .289, R^2\Delta = .025$). Table five (below) reports the standardised (β) and

unstandardised (B) regression coefficients for model one and model two. The BRIEF-2 was the only significant predictor of CAT-Q scores ($\beta = -.515$, $t(37) = 2.69$, $p = .011$).

Table 5

Standardised and unstandardized beta coefficients for model one and two when predicting self-rated camouflaging

	B	95% CI B	β	<i>t</i>	<i>p</i>
Model 1					
BRIEF-2	-1.329	-2.262 – -.396	-.546	2.88	.006
SRS	.838	-.147 - 1.824	.326	1.72	.093
Model 2					
BRIEF-2	-1.253	-2.196 - -.310	-.515	2.69	.011
SRS	.930	-.069 – 1.929	.362	1.89	.067
VIQ	.320	-.283 – .923	.169	1.08	.289

BRIEF-2: Behavioural Rating Inventory of Executive Function – 2nd Edition; SRS: Social Responsiveness Scale; VIQ: Verbal Intelligence Quotient.

Exploratory analysis: results by gender

Given the protective effect of VIQ against social communication difficulties, which is more evident in females compared to males (Skuse et al., 2009), exploratory analysis was conducted to assess if the above main findings persisted when separating the participants by sex/gender. Whilst moderation analysis would usually be used to investigate potential differences in camouflaging between each sex/gender, the current sample size would be underpowered to detect such an effect (see McClelland & Judd, 1993). Preliminary power analysis indicated a required sample of 92 for a medium effect size using the statistical programme, G*Power (Faul, Erdfelder, Lang & Buchner, 2007). As such, the above regression analyses were completed separately for each sex/gender.

A series of Pearson's correlations were conducted, separating each sex/gender (see table 6 & 7, below). Results indicated that for males, VIQ significantly correlated with CF ($r = .49, p = .035$), but not P-CAT-Q ($r = -.11, p = .620$) or CAT-Q ($r = .08, p = .726$). For females, VIQ significantly correlated with P-CAT-Q ($r = .59, p = .002$), and demonstrated a non-significant trend with CF ($r = .33, p = .097$), and CAT-Q scores ($r = .40, p = .054$).

Table 6

Correlation matrix with camouflaging variables and predictor variables for males

	CF	CAT-Q	P-CAT-Q	FSIQ	VIQ	NVIQ	BRIEF-2	SRS
CF								
CAT-Q	.09							
P-CAT-Q	.47*	.52**						
FSIQ	.59**	-.19	-.06					
VIQ	.49*	.08	-.11	.90**				
NVIQ	.53*	-.42	-.06	.93**	.69**			
BRIEF-2	-.09	-.41*	-.18	-.04	-.14	.04		
SRS	-.20	-.35	.10	-.30	-.43*	-.13	.67**	

* Correlation is significant at .05

** Correlation is significant at .01

CF: Discrepancy Camouflaging Scores; CAT-Q: Camouflaging of Autistic Traits Questionnaire; ; P-CAT-Q: Parent-report Camouflaging of Autistic Traits Questionnaire. FSIQ: Full Scale Intelligence Quotient; VIQ: Verbal Intelligence Quotient; NVIQ: Non-Verbal Intelligence Quotient; BRIEF-2: Behavioural Rating Inventory of Executive Function – 2nd Edition; SRS: Social Responsiveness Scale.

Table 7

Correlation matrix with camouflaging variables and predictor variables for females

	CF	CAT-Q	P-CAT-Q	FSIQ	VIQ	NVIQ	BRIEF-2	SRS
CF								
CAT-Q	.27							
P-CAT-Q	.26	.50*						
FSIQ	.15	.44*	.61**					
VIQ	.33	.40	.59**	.87*				
NVIQ	-.04	.33	.47*	.85**	.48*			
BRIEF-2	-.10	-.35	-.32	-.64**	-.46*	.56**		
SRS	-.17	-.02	-.25	-.49*	-.43*	-.37	.52**	

* Correlation is significant at .05

** Correlation is significant at .01

CF: Discrepancy Camouflaging Scores; CAT-Q: Camouflaging of Autistic Traits Questionnaire; ; P-CAT-Q: Parent-report Camouflaging of Autistic Traits Questionnaire. FSIQ: Full Scale Intelligence Quotient; VIQ: Verbal Intelligence Quotient; NVIQ: Non-Verbal Intelligence Quotient; BRIEF-2: Behavioural Rating Inventory of Executive Function – 2nd Edition; SRS: Social Responsiveness Scale.

Exploratory analysis: Is VIQ positively associated with camouflaging as measured by a discrepancy method for both males and females after controlling for executive functioning and autistic-like traits?

Hierarchical linear regression was used to understand if VIQ could significantly predict CF scores for both males and females separately after controlling for executive functioning and autistic-like traits. Of the 41 participants in the main analysis, 16 males and 25 females had complete CF, VIQ, BRIEF-2 and SRS measures. The first step of the hierarchical regression model included BRIEF-2 and SRS scores, with VIQ entered at step two.

For males, the first step indicated that the model did not significantly predict CF scores ($F(2, 13) = .05, p = .950$). When combined, BRIEF-2 and SRS scores

were found to predict approximately .8% of the variance in CF scores ($R^2 = .008$).

The second step indicated that the model still did not significantly predict CF scores ($F(3, 37) = .48, p = .704$), accounting for approximately 11% of the variance ($R^2 = .107$). Adding VIQ did not significantly improve the model's predictive value ($F(1, 37) = 1.33, p = .272, R^{2\Delta} = .099$).

For females, the first step of the model did not significantly predict CF scores ($F(2, 22) = .74, p = .490$). When combined, BRIEF-2 and SRS scores accounted for approximately 6% of the variance ($R^2 = .063$). The results for the second step indicated that the model still did not significantly predict CF scores ($F(3, 21) = 2.28, p = .109$), but now accounted for approximately 25% of the variance ($R^2 = .246$). Adding VIQ to the model significantly improved its predictive value ($F(1, 21) = 5.10, p = .035, R^{2\Delta} = .183$). Table 8 (below) reports the standardised (β) and unstandardised (B) regression coefficients for model one and model two for both sex/genders. VIQ was the only significant predictor of CF scores ($\beta = .500, t(21) = 2.26, p = .035$).

Table 8

Standardised and unstandardized beta coefficients for model one and two when predicting camouflaging discrepancy score by sex/gender

	Females					Males				
	B	95% CI B	β	<i>t</i>	<i>p</i>	B	95% CI B	β	<i>t</i>	<i>p</i>
Model 1										
BRIEF-2	-.005	-.017 – .007	-.217	.90	.377	.002	-.016 - .020	.083	.22	.819
SRS	.010	-.008 - .029	.281	1.16	.257	-.003	-.020 - .015	-.112	-.32	.756
Model 2										
BRIEF-2	-.001	-.012 - .010	-.045	.19	.850	-.001	-.020 - .018	-.056	-.15	.883
SRS	.015	-.003 – .032	.403	1.77	.091	.001	-.018 - .020	.047	.13	.903
VIQ	.009	.001 – .017	.500	2.26	.035	.006	-.005 - .017	.340	1.15	.272

BRIEF-2: Behavioural Rating Inventory of Executive Function – 2nd Edition; SRS: Social Responsiveness Scale; VIQ: Verbal Intelligence Quotient.

Exploratory analysis: Is VIQ positively associated with camouflaging as rated by parents for both males and females after controlling for executive functioning and autistic-like traits?

To investigate if VIQ could significantly predict P-CAT-Q scores for both males and females separately, after controlling for executive function and autistic-like traits, hierarchical regression was used. Of the 42 participants in the main analysis, 19 males and 23 females had completed P-CAT-Q, VIQ, BRIEF-2 and SRS. For the first step of the hierarchical regression, BRIEF-2 and SRS scores were entered into a model to predict CF scores. VIQ was entered at step two.

For males, the first model did not significantly predict P-CAT-Q scores ($F(2, 16) = .03, p = .973$). When combined, BRIEF-2 and SRS scores predicted approximately .3% of the variance ($R^2 = .003$). The second stage of the hierarchical regression model added VIQ to the analysis. The results indicated that the model still did not significantly predict P-CAT-Q scores ($F(3, 15) = .03, p = .993$), accounting for approximately .6% of the variance ($R^2 = .006$). Adding VIQ to the model did not improve its predictive value ($F(1, 15) = .03, p = .861, R^{2\Delta} = .003$).

For females, model one did not significantly predict P-CAT-Q scores ($F(2, 20) = 2.57, p = .102$). BRIEF-2 and SRS scores predicted approximately 20% of the variance in P-CAT-Q scores ($R^2 = .204$). When VIQ was added at step two, the model was now able to significantly predict P-CAT-Q scores ($F(3, 19) = 4.17, p = .020$), accounting for approximately 40% of the variance ($R^2 = .397$). Adding VIQ significantly improved the models predictive value ($F(1, 19) = 6.07, p = .023, R^{2\Delta} = .193$). Table 9 (below) reports the standardised (β) and unstandardised (B)

regression coefficients for model one and model two for females. VIQ was the only significant predictor of P-CAT-Q scores ($\beta = .512$, $t(19) = 2.46$, $p = .023$).

Table 9

Standardised and unstandardized beta coefficients for model one and two when predicting parent rated camouflaging by sex/gender

	Females					Males				
	B	95% CI B	β	<i>t</i>	<i>p</i>	B	95% CI B	β	<i>t</i>	<i>p</i>
Model 1										
BRIEF-2	-.868	-1.933 – .197	-.383	1.70	.105	-.129	-1.578 – 1.319	-.060	.19	.852
SRS	-.412	-2.028 – 1.204	-.120	.53	.601	.158	-1.319 – 1.634	-.072	.23	.824
Model 2										
BRIEF-2	-.448	-1.467 - .572	-.198	.92	.369	-.080	-1.693 – 1.533	-.037	.11	.917
SRS	-.006	-1.495 – 1.484	-.002	.01	.994	.115	-1.498 – 1.729	.053	.15	.881
VIQ	.837	.126 – 1.548	.512	2.46	.023	-.086	-1.116 – .944	-.050	.18	.861

BRIEF-2: Behavioural Rating Inventory of Executive Function – 2nd Edition; SRS: Social Responsiveness Scale;
VIQ: Verbal Intelligence Quotient.

Exploratory analysis: Is VIQ positively associated with self-rated camouflaging both males and females after controlling for executive functioning and autistic-like traits?

Hierarchical linear regression was used to understand if VIQ could significantly predict CAT-Q for both males and females separately, after controlling for executive function and autistic-like traits. Of the 41 participants in the main analysis, 18 males and 23 females had complete CAT-Q, VIQ, BRIEF-2 and SRS measures.

Preliminary analysis indicated that all necessary assumptions for linear regression were met, apart from normal distribution of errors for males. Due to the current research being exploratory in nature, and such a violation only limiting generalisation beyond the current sample (Field, 2009), the analysis continued as planned. For the first step of the hierarchical regression, BRIEF-2 and SRS scores were entered into a model to predict CAT-Q scores, with VIQ added at step two.

For males, step one of the model did not significantly predict CAT-Q scores ($F(2, 15) = 1.23, p = .302$). When combined, BRIEF-2 and SRS scores accounted for approximately 15% of the variance ($R^2 = .147$). The second step of the model added VIQ to the analysis. Results indicated that the model still did not significantly predict CAT-Q scores ($F(3, 14) = .85, p = .492$), with the model continuing to account for approximately 15% of the variance ($R^2 = .153$). Adding VIQ to the model did not significantly improve its predictive value ($F(1, 14) = .10, p = .758, R^{2\Delta} = .006$).

For females, model one indicated a non-significant trend when predicting CAT-Q scores ($F(2, 20) = 2.90, p = .078$). When combined, BRIEF-2 and SRS scores accounted for approximately 23% of the variance ($R^2 = .225$). When adding VIQ to the model, a non-significant trend in predicting CAT-Q scores continued

($F(3, 19) = 2.85, p = .065$), with approximately 31% of the variance accounted for ($R^2 = .311$). Adding VIQ to the model did not significantly improve its predictive value ($F(1, 19) = 2.36, p = .141, R^{2\Delta} = .086$). Table 10 (below) reports the standardised (β) and unstandardised (B) regression coefficients for model one and model two for females only.

Table 10

Standardised and unstandardized beta coefficients for model one and two when predicting self-rated camouflaging by sex/gender

	Females					Males				
	B	95% CI B	β	<i>t</i>	<i>p</i>	B	95% CI B	β	<i>t</i>	<i>p</i>
Model 1										
BRIEF-2	-1.440	-2.866 – -.193	-.538	2.41	.026	-.649	-2.282 – .985	-.319	.85	.411
SRS	1.090	-.840 – 3.021	.263	1.18	.253	-.162	-1.804 – 1.479	-.079	.21	.836
Model 2										
BRIEF-2	-1.113	-2.404 - .177	-.416	1.81	.087	-.606	-2.326 – 1.115	-.298	.76	.463
SRS	1.429	-.501 – 3.359	.345	1.55	.138	-.255	-2.073 – 1.563	-.125	.30	.768
VIQ	.675	-.245 – 1.594	.342	1.54	.141	-.137	-1.074 – .800	-.084	.31	.758

BRIEF-2: Behavioural Rating Inventory of Executive Function – 2nd Edition; SRS: Social Responsiveness Scale; VIQ: Verbal Intelligence Quotient.

Discussion

The association between VIQ and social camouflaging has previously been unclear, with comprehensive research lacking. The current research indicates that VIQ has a differential role in the camouflaging of autistic traits, depending upon the metric that is being used to quantify camouflaging. When using a discrepancy method, VIQ was found to be a significant, unique predictor of camouflaging behaviour, after controlling for executive functioning and autistic-like traits. VIQ was also found to significantly predict camouflaging as quantified by parental ratings. Whilst direct comparison is not possible, the amount of variance explained by VIQ was lower in parent-rated camouflaging than with discrepancy methods. Comparatively, VIQ was not able to predict self-rated social camouflaging.

Whilst the predictive value of VIQ differs across the measures of camouflaging, such results may reflect the different elements of camouflaging that are being assessed. As previously intimated (c.f. p.69), discrepancy methods can be thought of as mostly capturing camouflaging performance rather than camouflaging intent. That is to say, they best represent concealment of autistic traits in front of the assessing researcher or clinician. The current results therefore indicate that VIQ is an important predictor for successful camouflaging. When assessing camouflaging using a parent-rated measure, VIQ significantly predicted outcomes, but accounted for less variance than discrepancy measures. Such results could be interpreted as parent measures representing *some* elements of successful camouflaging, and *some* elements of unsuccessful camouflaging, given the observer position that the parent holds. Comparatively, reflective methods such as the CAT-Q are thought to represent an intent to camouflage, with current results suggesting that VIQ is less important in

this area. Taken together, these findings indicate that increased verbal ability may enable autistic individuals to appear more socially able than they really are.

The results of the current study are in accordance with previous research into VIQ's influence on social ability for autistic individuals. Verbal IQ has previously been linked with increased social functioning (Skuse et al., 2009), adaptive communication (Klin et al., 2007), and fewer social symptoms on the ADOS (Joseph et al., 2002). The current results naturally extend these findings, highlighting how VIQ contributes towards increased successful social camouflaging. It is however possible that previous links with increased social functioning, and fewer social symptoms may at least, in part, represent the successful incorporation of camouflaging strategies, rather than a 'true' difference in these areas. Given the known association between camouflaging behaviour and poor mental health (Bargeila et al., 2016; Cassidy et al., 2018; Hull et al., 2019; Lai et al., 2017), it is important to consider whether VIQ can be considered 'protective' against these social outcomes, as some of the above authors have claimed, or whether it is masking social and mental health difficulties. As such, future research may wish to investigate whether camouflaging may moderate the relationship between VIQ and the above social outcome variables.

This new understanding of VIQ's relationship with social camouflaging can now be used to increase awareness of the covarying abilities of those who may be concealing their social difficulties. This would be particularly beneficial for school teachers, families and primary care providers, who can often be the first to raise concerns regarding young people and trigger the necessary assessment protocols. Such information may alert individuals in these areas not to take language ability as

indicative of social functioning, and consider the possibility of this masking a true underlying social communication difficulty.

The current results may also be helpful for clinicians working within autism diagnostic services. As previously intimated, camouflaging has the potential to increase missed or misdiagnosis of autism (Lai & Baron-Cohen, 2015), whilst neuropsychological profile analysis can help explain individual functioning (Miller et al., 2015). It is therefore clear that intelligence testing must be incorporated within autism assessment protocols to assist with wholistic formulation; particularly for children who may not present with obvious social difficulties and would otherwise be at risk of not receiving a diagnosis and the associated support. It is however important to emphasise that there are no cut off scores during intelligence tests that can be used to identify children as being ‘at risk’ of camouflaging or not. As such, the incorporation of intelligence tests should form part of a broader formulation. Given the known relationship between camouflaging and depression, anxiety, reduced wellbeing and suicidality (Bargeila et al., 2016; Cassidy et al., 2018; Hull et al., 2019; Lai et al., 2017), such improved diagnostic accuracy and intervention could, in turn, improve mental health prognosis.

Whilst statistically non-significant, it is of interest that autistic-like traits approached significance as a predictor for the camouflaging discrepancy score. Such results suggest that increased autistic-like traits, along with VIQ, can predict camouflaging performance. These findings are in line with previous research that demonstrated higher autistic-traits lead to more autistic behaviours to be camouflaged for (Hull et al., 2019). The current results now provide further information about predictors of camouflaging performance, which can be potentially

utilised to improve diagnostic accuracy and subsequent mental health outcomes for some autistic individuals.

Whilst the exploratory research completed here should be interpreted with caution due to its lack of statistical power, the results highlight potential sex differences in terms of the role of VIQ in successful camouflaging. For females, VIQ was a significant predictor of successful and parent-rated camouflaging, but not intention to camouflage, as measured by a self-rated camouflaging measure. Whilst the current findings were underpowered, these results did not hold for males, where VIQ did not significantly predict scores on any measure of camouflaging. Such results appear unsurprising given the previous demonstration of increased VIQ protecting against communication difficulties for females, which did not hold for males with above average VIQ scores (Skuse et al., 2009). It is possible that, when attempting to camouflage, females draw upon more compensatory skills, such as the creation of scripts for conversation. Conversely, males may rely more upon masking abilities, such as the concealment of self-stimulatory behaviour. As such, females may use more verbal abilities in order to successfully camouflage. Future research may therefore wish to consider the generalisation of VIQ contributing towards successful camouflaging across both sexes/genders, and further investigate the critical components of successful camouflaging across both sexes/genders.

Despite the current research highlighting a significant role for VIQ in successful social camouflaging, it is possible that this relationship has been underestimated due to the current methodology. The discrepancy measures used in the current research can provide estimations of successful camouflaging, however, there is a reliance upon the individual being motivated to camouflage within the assessment context (Cage & Troxell-Whitman, 2019). As such, results may not

reflect the participants' *ability* to successfully camouflage, but instead a combination of motivation and ability. Prior research has indicated that increased job opportunities, fitting in with others, and social connections can motivate camouflaging behaviour (Cage & Troxell-Whitman; Hull et al., 2017). Given that the children taking part in the research were aware that they were participating in an autism specific study, it is unclear as to what extent these motivations to camouflage would have been applicable. The research may therefore have missed individuals who *can* successfully camouflage, but are opting not to do so, due to the motivating factors not being applicable to the situation. Future research into camouflaging using discrepancy methods in particular should seek to understand the motivating factors for camouflaging in each individual, and account for this as necessary.

The current research represents one of the most comprehensive investigations into social camouflaging. Rather than using a single metric, the research utilised three different, but complementary methods, to measure camouflaging. Incorporating these different methodologies enabled the research to look beyond social camouflaging as a one-dimensional entity. Instead, the different aspects, such as successful performance and camouflaging intention were measured, with different roles for VIQ in each of these processes. The current research demonstrated significant, but not perfect, correlations between each measure. This suggests that, whilst camouflaging tools overlap, there are important distinctions to be drawn. Future research into social camouflaging should now consider which aspects of camouflaging they are intending to measure and incorporate an appropriate tool to answer such questions.

Whilst VIQ was not a significant predictor of self-rated camouflaging, executive functioning was. This result contrasts with executive functioning not being

a significant unique predictor of parent-rated or camouflaging discrepancy scores. The current results indicate that executive functioning appears more important when reflecting upon intention to camouflage, rather than camouflaging performance. It is possible that these results reflect the known relationship between executive functioning and metacognition (Best & Miller, 2010). As such, increased awareness and understanding of one's thought processes may result in higher self-reported camouflaging scores, as camouflaging behaviour is more conscious than unconscious. Future research may wish to investigate this potential relationship further.

Limitations

Whilst the current research was able to investigate VIQ's role in camouflaging behaviour, it is not without its limitations. Firstly, it should be noted that the WASI-II is a brief measure of intelligence, designed as a screening tool to estimate FSIQ. Results from this would usually be used to indicate whether further in-depth intellectual assessment is required. For the older individuals within this sample, further intellectual assessment would use the Wechsler Adult Intelligence Scale – 4th Edition (WAIS-IV; Wechsler, 2010), which requires further subtest administration to calculate the Verbal Comprehension Index score. It is therefore unclear as to whether the current results would continue, if an in-depth intellectual assessment was completed.

It should also be noted that the use of VIQ reflects a two-factor solution of intelligence that is not in line with current conceptualisations. The current iteration of the Wechsler Intelligence Scale for Children, (WISC-V; Wechsler, 2016) supports a five-factor model of intelligence, including verbal comprehension, visual spatial

ability, fluid reasoning, working memory, and processing speed. The current research was therefore not able to investigate other intellectual indices. One potential ability that may be important for camouflaging is processing speed, which is higher in late diagnosed females (Lehnhardt et al., 2016). When combined with the above limitation of the WASI-II being a brief measure of intelligence, future research in this area may wish to consider incorporating more in-depth assessment tools that go beyond a two-factor solution of intelligence. Such research could then compare the relative importance of each index in successful camouflaging.

Whilst the current research conceptualised VIQ performance as indicative of verbal ability alone, it should be recognised that performance on measures of VIQ covary with other cognitive abilities. Prior research has highlighted the correlation higher VIQ and better performance on ToM tasks for autistic children (Happé, 1995; Pilowsky, Yirmiya, Arbelle & Mozes, 2000). As such, the current association between VIQ and camouflaging may also partly reflect increased ToM capability, which was not included within the current analysis. To assess a purer relationship between verbal ability and camouflaging, future research may therefore wish to measure and control for ToM ability during all analyses.

A further limitation of the current research is the use of multiple contexts when conducting the assessment process. As noted by Cage & Troxell-Whitman (2019), camouflaging behaviour can be influenced by context in which an individual is placed. During the data collection, some children completed the assessment in their school; others travelled to the UCL testing rooms, and some were visited at home. It is possible that the different contexts of assessment, which were offered to provide convenience for each participant, may have led to some individuals camouflaging more or less than they would have done, had the assessment been

completed elsewhere. Future research may therefore wish to maintain consistency across participant context, or assess the current motivation to camouflage, and take this into consideration when evaluating camouflaging behaviour.

Whilst a strength of the current research was the ability to measure the influence of VIQ in social camouflaging, over and above executive functioning, it should be noted that the current method of measuring executive functioning has its limitations. Firstly, the general executive component of the BRIEF used here is an overall summary of executive functioning that incorporates all the BRIEF subscales. This was used in a hypothesis free manner, due to the available research providing limited specific information as to which executive abilities may be more or less related to social camouflaging. However, incorporating a single measure of executive functioning assumes that all executive abilities are equally developed. Prior research has instead demonstrated that executive ability can fractionate, with relative strengths and weaknesses demonstrable in autistic children (Granader et al., 2014). In addition, the use of a questionnaire does not allow direct assessment of executive functioning. Despite this enabling a broader reflection of executive ability through the general executive component of the BRIEF, it relies upon accurate parent reflection of such abilities. As such, future research into executive functioning and social camouflaging may wish to investigate which specific abilities (or difficulties) impact camouflaging behaviour/success, using direct measures of executive functioning.

It should be noted that the current research was completed with adolescents only, making the results difficult to generalise to other age ranges. Whilst research in this area is in its infancy, there are preliminary findings to suggest that camouflaging changes across the lifespan (Ormond, Brownlow, Garnett, Rynkiewicz & Attwood,

2018). As such, it is equally possible that the role of VIQ in successful camouflaging may change across the lifespan, potentially with verbal strategies more important in childhood and adolescence compared to adulthood. Such an interpretation could help explain the differential results obtained here, compared to those from Lai et al. (2017), whose research was completed with adults. Future research may therefore wish to investigate whether VIQ is an equally important contributor towards successful social camouflaging at all life stages.

The current research was also limited during the data collection stage. In particular, four different individuals were involved in completing the ADOS. Despite calibration meetings being conducted, no formal inter-rater reliability assessment was completed. Whilst the ADOS has previously demonstrated good inter-rater reliability (Hus & Lord, 2014), future replication of the current research should incorporate reliability analysis when using the ADOS.

The possibility of greater camouflaging scores reflecting more autistic behaviours to be camouflaged for was controlled by using the SRS during all analysis, however such a questionnaire contains inherent limitations. The SRS investigates autistic-like behaviours in social situations. It is possible that scores on this measure are therefore influenced by social camouflaging. As such, the questionnaire may not be providing a pure measure of autistic-like traits in all contexts, but instead only those that appear in social environments. Future research may wish to consider this limitation, and potentially utilise an alternative measure of autistic-like traits.

Finally, the current research was limited by low statistical power. Calculations prior to the research indicated that 77 participants would be required for a medium effect size. However, the study only managed to successfully recruit 59

participants. Furthermore, during statistical analysis, only 41 or 42 participants had complete datasets to enable inclusion. The lack of necessary statistical power was further evident during exploratory analysis, where participant numbers were lower than what would be recommended, based upon the number of predictor variables used (i.e. 10 participants per variable; see Jenkins & Quintana-Ascencio, 2020). It is possible that the lack of complete data may represent the difficulties in utilising multiple assessment tools within one assessment session. Future research may therefore wish to investigate the acceptability of the current assessment protocol, and consider whether multiple assessment sessions, or a reduced number of measurement tools would increase recruitment and completion of all data.

Future research

Notwithstanding the limitations of the current study, the role of VIQ in successful camouflaging should now be considered as a springboard for future research. Despite the combination of VIQ, executive functioning and autistic traits as a model predicting successful camouflaging, a large proportion of variance was unaccounted for. Such results raise further questions about other contributing factors that may facilitate successful camouflaging. Given that camouflaging is thought to be a complex social-cognitive process (Cassidy et al., 2018), it is possible that cognitive abilities such as processing speed may be required to make real time adaptations to one's environment. Conversely, it is possible that some unaccounted variance may be explainable by non-cognitive abilities, for example, personality traits, which may influence interpersonal behaviour and response choice when in social situations, thus impacting camouflaging. Taken together, future research should now seek to

understand the additional factors that may help explain successful social camouflaging.

Future research may also wish to consider if further verbal abilities that are not directly assessed by VIQ can influence successful camouflaging. One potential candidate could be listening comprehension skills, measured by the Wechsler Individual Achievement Test, third edition (WIAT-III; Wechsler, 2017). This subscale investigates an individual's receptive vocabulary (by matching words and concepts), and oral discourse comprehension (by making inferences and remembering details from discourse). In addition, skills such as word fluency (i.e. rapid production of words within a specific concept) could also link to successful camouflaging. As such, future research should endeavour to further understand whether specific verbal abilities are being drawn upon during social interactions to increase successful camouflaging.

Conclusions

The current research utilised three different measures of social camouflaging to investigate a potential relationship with VIQ. The results indicated a significant role of VIQ in both camouflaging rated by a discrepancy measure, and camouflaging behaviour when rated by a parent. However, VIQ did not contribute towards self-rated camouflaging. Such results indicate that VIQ is important for successfully camouflaging autistic traits, but less important for camouflaging intention. These results should now be used to increase teachers, parents and primary care providers knowledge of VIQ's role in successful camouflaging. Such results should also be used by clinicians within autism diagnostic services to help reduce missed or

misdiagnosis. Further research should now seek to understand what further cognitive abilities may be involved in successful camouflaging.

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Part 3: The Critical Appraisal

Summary

The following includes my reflections on completing the literature review and research project for this thesis. I provide information about my context to highlight how this interacted with many of the choices made throughout the process. I first reflect upon the initial stages of choosing a project, before discussing the process of completing the thesis, and consider the potential future for social camouflaging research.

Background

Prior to starting clinical training, I worked across multiple areas of psychology, but was frequently involved in neuropsychological assessments. The bulk of this experience was across two jobs: one as an Assistant Psychologist within an inner-city neurological hospital, and one where I was required to travel across the UK completing neuropsychological assessments with Looked After Children. In terms of research experience, prior to clinical training, I completed a research methods masters' degree, and always enjoyed using quantitative methodologies. When combined with my personal experience of autism in my family, I felt driven to conduct research using neuropsychological assessment tools in the field of autism.

Choosing a Project

When looking into a potential project, I had a strong desire to use a quantitative methodology, and to maintain a neuropsychological slant on whichever project I was

completing. In addition, I was advised by a former Trainee Clinical Psychologist to select an overarching topic that I would be interested in, given the amount of time that would be dedicated to the project. In addition, the Trainee Psychologist advised me to find a project that was already recruiting, or used an existing dataset, in order to avoid the lengthy process of gaining ethical approval. I was therefore pleased to come across a project that was already recruiting participants. Social camouflaging in autism was not something I was aware of before starting clinical training. As such, the novelty of the project also appealed to me, along with the potential to be involved in the cutting edge of this research field.

Research Process

Literature review

When considering a topic for the literature review, I noticed myself feeling somewhat guilty in comparison to others in my cohort, as I was able to join a project that was already up and running. As a result, I felt compelled to undertake an ambitious, and hopefully very publishable literature review. When I first discussed ideas with my supervisor, I wanted to ensure that my review would be systematic and have a strong critical appraisal component. In addition, I wanted to produce something that would be useful to researchers and clinicians working within neurodevelopmental services. As such, my initial ideas were focused upon conducting a systematic review of every measurement tool of camouflaging, with an overall traffic light system that would allow researchers and clinicians to look down a table and choose a tool with the best available evidence. As I embarked on this project, I came to realise that answering this question might not be possible, as the

available measures do not investigate identical aspects of camouflaging. Some measures are best placed to assess successful camouflaging, whilst others are better placed to assess camouflaging intention. In addition, many of the tools used to investigate camouflaging focus on specific behaviours that may increase the likelihood of successfully camouflaging, such as speech patterns and body movements (e.g. Parish-Morris et al., 2017; Rynkiewicz et al., 2016), but are not themselves representative of overall camouflaging. My focus therefore had to reluctantly shift towards investigating the psychometric properties of these available measures, taking less of a comparative focus. Whilst this was initially disappointing, on reflection, I have come to realise that this highlights how social camouflaging research is at an early stage, and that comparison of different measurement tools will become more likely in the future as the camouflaging literature evolves.

Data collection challenges

As part of joining a research project that was already underway, I was informed that data collection would begin immediately. Given the amount of time that we had available to recruit (approximately two years), I believed that we would be able to reach our required sample size, very comfortably. I was all the more confident given my previous research experience in the Oxford BabyLab where we were able to recruit approximately 40 three-month old babies within three months. As time went on, it was clear that recruitment was going to be difficult. As there were four of us conducting the research, we decided to focus upon different regions of the UK that we had ties to, communicating with support groups and local clinics to advertise our study. However, the area I was trying to recruit from did not have anyone come forward to take part in the research. Comparatively, my colleague who was recruiting

in Kent was able to make contact with a person who identified as an ‘autism advocate’. Rather than finding contact through support groups, the advocate was able to advertise our research through Facebook groups, affirming the necessity of the project. As I have reflected upon the research project, I have thought about how us, as a research team, may have come across as supposed ‘experts’, infiltrating a safe space in terms of the support groups. We may have appeared more concerned with completing research for the requirements of our course, instead of doing it for the benefit of the autistic community. I have come to realise how the incorporation of an autistic advocate may have helped us bridge the gap between ourselves and the participants, making us appear potentially less threatening.

One of the ways we attempted to combat recruitment difficulties was to offer a prize draw using our research fund, however, recruitment did not appear to increase. Whilst all the families were informed about the prize draw, the conversations I was having after completing the research focused on the possibility for this reducing missed or misdiagnosis within neurodevelopmental services. Instances where I spoke to families about prizes, to inform that I would be in touch if they won, were often met with quizzical reactions. Many families would tell me that the prizes were not part of their motivation to take part. Instead, they hoped that they could, in some way, try to make a difference. More often than not, families would speak to me about obtaining a copy of the results when they became available. Such reactions highlighted to me that, when we were attempting to recruit, it may have been beneficial to make it more salient to participants how this research could change clinical practice.

Another way we attempted to increase participation in the research was by contacting multiple NHS trusts, however, we quickly learnt how difficult it was to

recruit from multiple sites. From a patient experience perspective, it can be possible to navigate through multiple NHS trusts seamlessly; for example, many children can be seen within their local trusts, but also seen at specialist services such as Great Ormond Street Hospital. However, the trust-based system can make conducting research very difficult. This was evident when contacting my local neurodevelopmental service, who principally agreed that we could recruit from their service, but that we would need to amend our ethical approval to add themselves as a Patient Identification Site (PIC), as well as obtain a research passport. Whilst we completed the required steps for my local service, this occurred after we presented the research to a team of clinicians. There was a lengthy delay between research presentation, and study approval within the trust. I have continually reflected upon how the NHS, from a research point of view, can feel fractured and difficult to navigate between sites. I have also often reflected upon whether the delay led clinicians in the service to have forgotten about the importance of the research project, leading to it not being advertised.

Dual role as Trainee Clinical Psychologist and Researcher

Throughout data collection, I often felt conflicted when trying to balance my dual role as a Trainee Clinical Psychologist and a Researcher; particularly when asked to assist with clinical matters. When visiting families at their homes, I would often be asked about my involvement with the project. As part of this, I would explain that I was a Trainee Clinical Psychologist, and that this research was part of my major research project. After completing data collection, I received contact from three families, who asked me to write a supporting statement for things such as personal independence payments, or to request changes in their child's Education, Health and

Care Plan. This was something that created a moral conflict for me. Whilst I knew that I would not be able to support their requests, I reflected upon how frustrating this situation would be from their point of view, given that they had supported our research project. As such, we may have been showing very little reciprocity in terms of providing help. This situation was made all the more difficult given that the placement I was in during the main part of the data collection process involved writing supporting statements for children in similar situations. As such, the situation often left me feeling conflicted by wanting to help, but not being able to do so. As I have continued to reflect upon this, I have realised that we could have worked closer with our autistic advocate, and put in place a system whereby, if such concerns were to arise, they could have been put in touch with the advocate to help navigate these situations.

Targeting the right group

During data collection, I often found myself reflecting upon the group we were targeting for the research (i.e. those with a confirmed diagnosis of an autistic spectrum disorder), and whether we could have approached this differently. After finishing the testing protocol, I always offered families the opportunity to ask any questions or make any comments. This would often lead families, particularly of autistic females, to tell me about their difficulties in receiving a diagnosis. These families explained to me how they had visited their local neurodevelopmental service when their child was younger but were told that their child did not meet the criteria for autism. For most, their child did not receive a diagnosis until their mental health began to be impacted, resulting in a reassessment. As time continued, I started to think about the sample of children we were recruiting into our study, and whether we

should focus on children who had required multiple assessments to reach a diagnosis. Such research could have provided vital information about children who are most successful in terms of camouflaging, as they have been able to hide their autistic symptomology in front of trained clinicians at an earlier time point. This is something that should be considered when recruiting participants in future camouflaging research.

Answering the question at hand

As the project proceeded, I often reflected upon my desire to contribute towards a research area using neuropsychological tools, and whether this overshadowed other potential avenues of research. Whilst my specific question of interest centred around whether verbal intelligence may underpin social camouflaging in autism, my overarching goal was to answer the question about whether autistic children may be more likely to, or more successful at camouflaging, when incorporating complex language. At a broader level, I was wanting to understand whether autistic children who use such complex language when interacting with teachers or other care providers may be less likely to enter the autism assessment process. As the research continued, I have thought more about other ways to answer this question without relying upon neuropsychological tools. One potential way to answer such a question is to use a methodology similar to Hiller, Young and Weber (2014), where the teacher reported on behaviours such as the child's ability to maintain reciprocal communication. Such a methodology would have enabled verbal abilities within my context of interest to be measured. This may be an avenue for researchers in the future.

Data analysis

Whilst I felt comfortable using any necessary statistical method to analyse our data, I found myself debating exactly how I could best answer my research questions. This was particularly pertinent when considering how to control for executive functioning (EF) throughout our analysis. The available research demonstrates a relationship between EF and camouflaging (e.g. Lai et al., 2017; Livingston, Colvert, SRST, Bolton & Happé, 2019). This research has utilised behavioural measures of EF, focusing upon specific abilities such as response inhibition and set shifting. Whilst these results have highlighted the relationship between EF and social camouflaging, they have not provided comprehensive information about which specific executive abilities may be more or less related to camouflaging. Given this lack of information, I decided to take the broadest view possible, however, future research may wish to investigate this area further. In addition, I found myself considering whether further analysis about which verbal subtests (i.e. vocabulary or similarities) may best relate to social camouflaging, given that each test is proposed to have higher and lower verbal loadings (Keuhnel, Castro & Furey, 2019). However, I started to become concerned that continual analysis could inflate type one error rate. As such, I resisted from continually analysing the same dataset.

Terminology

Whilst the term social camouflaging has been used throughout the research project, it is important to reflect upon my experience of using this term when conducting the research. The term is often used to emphasise the way in which autistic individuals

blend into social situations (Dean, Harwood & Kasari, 2017). Whilst this a common term used throughout the academic literature, it was often a term that did not resonate with the families I met. Throughout the research project, participants and their families would often use the term ‘masking’ to refer to all behaviours that would hide autistic characteristics. Many would explain to me that ‘masking’ reflected their belief that they were putting a mask on when they were in public places. Contrastingly, the academic literature considers masking to be a subcomponent of camouflaging, along with compensation (Lai et al., 2011). As this area of research evolves, it is important to recognise that this term may not fit with the experiences of many within the autistic community, and has the potential to promote a power imbalance, with researchers being the holder of ‘official’ terminology. Future research may wish to investigate preferred terminology to ensure it is commensurate with the experiences of those in the autistic community.

Changing Reflections on Camouflaging

Throughout the research, I frequently found myself shifting position in terms of whether camouflaging should be discouraged, or whether there are situations where it could be promoted. This shifting position started early during the research project when we were required to put together a research proposal. When I reviewed the available literature at the time, I came across a newly published study that highlighted the links between camouflaging and suicidality (Cassidy, Bradley, Shaw & Baron-Cohen, 2018). Such research led me to believe that camouflaging should be discouraged in all formats. However, when my proposal was reviewed, there were comments about considering the potential benefits of camouflaging. This was

something I found difficult to read at the time, given the links to suicidality, but as time went on, I further engaged with the qualitative literature, particularly from Hull et al. (2017). This research highlighted how some individuals found camouflaging to help minimise stress during ‘small talk’ and allowed people to connect better. After reading this, I started to consider how, in certain instances, camouflaging may provide positive experiences. Over time, I have come to the conclusion that the effects of camouflaging can be very negative, particularly in terms of limiting access to services and poorer mental health, but that camouflaging itself is not *always* the issue. Instead, some difficulties can occur because of a lack of understanding people have about camouflaging, particularly through the diagnostic and help seeking process, which then have a profound impact upon personal experiences. Whilst there will undoubtedly be individuals who experience negative effects from the stresses and strains of engaging in camouflaging behaviour, it must be considered in context, as the impact of camouflaging will change from person to person. Understanding the person’s relationship to camouflaging must form part of a comprehensive formulation to understand its impact on the individual.

Where Does the Camouflaging Research Go from Here?

As the research progressed, I have frequently reflected upon the current state of camouflaging literature. One area where camouflaging researchers may wish to focus is on improving the ‘responsiveness’ of the available measures. When evaluating the measures of camouflaging during the literature review, no measure sought to understand whether their scores would alter in the face of a true change in camouflaging behaviour. When I first began reflecting on this, I considered whether

it would be of importance. However, as time has moved on, I have come to think about how little we currently understand in terms of how camouflaging changes over the lifespan. Given the known links between camouflaging and poor mental health variables (Bargiela, Steward & Mandy, 2016; Cassidy et al., 2018; Hull et al., 2019; Lai et al., 2017), it seems important to understand if there are critical ages where camouflaging may peak. This improved knowledge could help proactively provide necessary support and interventions. As such, the requirement for a measure to be responsive should be considered as the camouflaging field moves forward.

Invariably, it is of high importance that camouflaging researchers now consider how best the available research could integrate with clinical practice. When I reviewed the current measures of camouflaging, it was clear that there were some preliminary indications of valid and reliable tools to assess such behaviour, particularly the CAT-Q (Hull et al., 2019). In addition, tools such as the Cage Questionnaires (Cage & Troxell-Whitman, 2019) were helping to provide a greater understanding of where camouflaging may be more common, and what the motivating factors are for some individuals. However, how these measures now translate into the clinical domain is not immediately obvious. At present, there are no group norms for the CAT-Q or Cage Questionnaires. Moreover, there is no information about how to interpret such measures, and whether the scores reflect high, low, or average levels of camouflaging. I believe that it is now the challenge of camouflaging researchers to consider how best to incorporate this knowledge into the clinical domain to help reduce the likelihood of children being missed, or misdiagnosed.

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Appendix A – COSMIN Checklist with 4-Point Scale

COSMIN checklist with 4-point scale

Contact
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Instructions

This version of the COSMIN checklist is recommended for use in systematic reviews of measurement properties. With this version it is possible to calculate overall methodological quality scores per study on a measurement property. A methodological quality score per box is obtained by taking the lowest rating of any item in a box ('worse score counts'). For example, if for a reliability study one item in the box 'Reliability' is scored poor, the methodological quality of that reliability study is rated as poor. The Interpretability box and the Generalizability box are mainly used as data extraction forms. We recommend to use the Interpretability box to extract all information on the interpretability issues described in this box (e.g. norm scores, floor-ceiling effects, minimal important change) of the instruments under study from the included articles. Similar, we recommend to use the Generalizability box to extract data on the characteristics of the study population and sampling procedure. Therefore no scoring system was developed for these boxes.

This scoring system is described in this paper:

Terwee CB, Mokkink LB, Knol DL, Ostelo RWJG, Bouter LM, de Vet HCW. Rating the methodological quality in systematic reviews of studies on measurement properties: a scoring system for the COSMIN checklist. *Quality of Life Research* 2012.⁶⁰⁴

Step 1. Evaluated measurement properties in the article

	Internal consistency	Box A
	Reliability	Box B
	Measurement error	Box C
	Content validity	Box D
	Structural validity	Box E
	Hypotheses testing	Box F
	Cross-cultural validity	Box G
	Criterion validity	Box H
	Responsiveness	Box I

Step 2. Determining if the statistical method used in the article are based on CTT or IRT

Box General requirements for studies that applied Item Response Theory (IRT) models		excellent	good	fair	poor
1	Was the IRT model used adequately described? e.g. One Parameter Logistic Model (OPLM), Partial Credit Model (PCM), Graded Response Model (GRM)	IRT model adequately described	IRT model not adequately described		
2	Was the computer software package used adequately described? e.g. RUMM200, WINSTEPS, OPLM, MULTILOG, PARSCALE, BILOG, NLMIXED	Software package adequately described	Software package not adequately described		
3	Was the method of estimation used adequately described? e.g. conditional maximum likelihood (CML), marginal maximum likelihood (MML)	Method of estimation adequately described	Method of estimation not adequately described		
4	Were the assumptions for estimating parameters of the IRT model checked? e.g. unidimensionality, local independence, and item fit (e.g. differential item functioning (DIF))	assumptions of the IRT model checked	assumptions of the IRT model partly checked	assumptions of the IRT model not checked or unknown	

To obtain a total score for the methodological quality of studies that use IRT methods, the "worse score counts" algorithm should be applied to the IRT box in combination with the box of the measurement property that was evaluated in the IRT study. For example, if IRT methods are used to study internal consistency and item 4 in the IRT box is scored fair, while the items in the internal consistency box (box A) are all scored as good or excellent, the methodological quality score for internal consistency will be fair. However, if any of the items in box A is scored poor, the methodological quality score for internal consistency will be poor.

Step 3. Determining if a study meets the standards for good methodological quality

Box A. Internal consistency		excellent	good	fair	poor
1	Does the scale consist of effect indicators, i.e. is it based on a reflective model?				
<i>Design requirements</i>					
2	Was the percentage of missing items given?	Percentage of missing items described	Percentage of missing items NOT described		
3	Was there a description of how missing items were handled?	Described how missing items were handled	Not described but it can be deduced how missing items were handled	Not clear how missing items were handled	
4	Was the sample size included in the internal consistency analysis adequate?	Adequate sample size (≥ 100)	Good sample size (50-99)	Moderate sample size (30-49)	Small sample size (< 30)
5	Was the unidimensionality of the scale checked? i.e. was factor analysis or IRT model applied?	Factor analysis performed in the study population	Authors refer to another study in which factor analysis was performed in a similar study population	Authors refer to another study in which factor analysis was performed, but not in a similar study population	Factor analysis NOT performed and no reference to another study
6	Was the sample size included in the unidimensionality analysis adequate?	$\geq 7^*$ items and ≥ 200	5^* items and ≥ 100 OR $6-7^*$ items but < 100	5^* items but < 100	$< 5^*$ items

7	Was an internal consistency statistic calculated for each (unidimensional) subscale separately?	Internal consistency statistic calculated for each subscale separately		Internal consistency statistic NOT calculated for each subscale separately
8	Were there any important flaws in the design or methods of the study?	No other important methodological flaws in the design or execution of the study	Other minor methodological flaws in the design or execution of the study	Other important methodological flaws in the design or execution of the study
<i>Statistical methods</i>				
9	for Classical Test Theory (CTT), continuous scores: Was Cronbach's alpha calculated?	Cronbach's alpha calculated	Only item-total correlations calculated	No Cronbach's alpha and no item-total correlations calculated
10	for CTT, dichotomous scores: Was Cronbach's alpha or KR-20 calculated?	Cronbach's alpha or KR-20 calculated	Only item-total correlations calculated	No Cronbach's alpha or KR-20 and no item-total correlations calculated
11	for IRT: Was a goodness of fit statistic at a global level calculated? (e.g. χ^2 , reliability coefficient of estimated latent trait value (index of subject or item) separation)	Goodness of fit statistic at a global level calculated		Goodness of fit statistic at a global level NOT calculated

NB. Item 1 is used to determine whether internal consistency is relevant for the instrument under study. It is not used to rate the quality of the study.

Box B. Reliability: relative measures (including test-retest reliability, inter-rater reliability and intra-rater reliability)				
Design requirements	excellent	good	fair	poor
1. Was the percentage of missing items given?	Percentage of missing items described	Percentage of missing items NOT described		
2. Was there a description of how missing items were handled?	Described how missing items were handled	Not described but it can be deduced how missing items were handled	Not clear how missing items were handled	
3. Was the sample size included in the analysis adequate?	Adequate sample size (≥ 100)	Good sample size (50-99)	Moderate sample size (30-49)	Small sample size (< 30)
4. Were at least two measurements available?	At least two measurements			Only one measurement
5. Were the administrations independent?	Independent measurements	Assumable that the measurements were independent	Doubtful whether the measurements were independent	measurements NOT independent
6. Was the time interval stated?	Time interval stated		Time interval NOT stated	
7. Were patients stable in the interim period on the construct to be measured?	Patients were stable (evidence provided)	Assumable that patients were stable	Unclear if patients were stable	Patients were NOT stable
8. Was the time interval appropriate?	Time interval appropriate		Doubtful whether time interval was appropriate	Time interval NOT appropriate
9. Were the test conditions similar for both measurements? e.g. type of administration, environment, instructions	Test conditions were similar (evidence provided)	Assumable that test conditions were similar	Unclear if test conditions were similar	Test conditions were NOT similar

10	Were there any important flaws in the design or methods of the study?	No other important methodological flaws in the design or execution of the study	Other minor methodological flaws in the design or execution of the study	Other important methodological flaws in the design or execution of the study
<i>Statistical methods</i>				
11	for continuous scores: Was an intraclass correlation coefficient (ICC) calculated?	ICC calculated and model or formula of the ICC is described	ICC calculated but model or formula of the ICC not described or not optimal. Pearson or Spearman correlation coefficient calculated with evidence provided that no systematic change has occurred	Pearson or Spearman correlation coefficient calculated WITHOUT evidence provided that no systematic change has occurred or WITH evidence that systematic change has occurred
12	for dichotomous/nominal/ordinal scores: Was kappa calculated?	Kappa calculated		Only percentage agreement calculated
13	for ordinal scores: Was a weighted kappa calculated?	Weighted Kappa calculated	Unweighted Kappa calculated	Only percentage agreement calculated
14	for ordinal scores: Was the weighting scheme described? e.g. linear, quadratic	Weighting scheme described	Weighting scheme NOT described	

Box C: Measurement error: absolute measures				
	excellent	good	fair	poor
<i>Design requirements</i>				
1	Was the percentage of missing items given?	Percentage of missing items described	Percentage of missing items NOT described	
2	Was there a description of how missing items were handled?	Described how missing items were handled	Not described but it can be deduced how missing items were handled	Not clear how missing items were handled
3	Was the sample size included in the analysis adequate?	Adequate sample size (≥ 100)	Good sample size (50-99)	Moderate sample size (30-49) Small sample size (< 30)
4	Were at least two measurements available?	At least two measurements		Only one measurement
5	Were the administrations independent?	Independent measurements	Assumable that the measurements were independent	Doubtful whether the measurements were independent measurements NOT independent
6	Was the time interval stated?	Time interval stated		Time interval NOT stated
7	Were patients stable in the interim period on the construct to be measured?	Patients were stable (evidence provided)	Assumable that patients were stable	Unclear if patients were stable Patients were NOT stable
8	Was the time interval appropriate?	Time interval appropriate		Doubtful whether time interval was appropriate Time interval NOT appropriate
9	Were the test conditions similar for both measurements? e.g. type of administration, environment, instructions	Test conditions were similar (evidence provided)	Assumable that test conditions were similar	Unclear if test conditions were similar Test conditions were NOT similar

10	Were there any important flaws in the design or methods of the study?	No other important methodological flaws in the design or execution of the study	Other minor methodological flaws in the design or execution of the study	Other important methodological flaws in the design or execution of the study
<i>Statistical methods</i>				
11	For CTT: Was the Standard Error of Measurement (SEM), Smallest Detectable Change (SDC) or Limits of Agreement (LoA) calculated?	SEM, SDC, or LoA calculated	Possible to calculate LoA from the data presented	SEM calculated based on Cronbach's alpha, or on SD from another population

Box D. Content validity (including face validity)					
		excellent	good	fair	poor
<i>General requirements</i>					
1	Was there an assessment of whether all items refer to relevant aspects of the construct to be measured?	Assessed if all items refer to relevant aspects of the construct to be measured		Aspects of the construct to be measured poorly described AND this was not taken into consideration	NOT assessed if all items refer to relevant aspects of the construct to be measured
2	Was there an assessment of whether all items are relevant for the study population? (e.g. age, gender, disease characteristics, country, setting)	Assessed if all items are relevant for the study population in adequate sample size (≥ 10)	Assessed if all items are relevant for the study population in moderate sample size (5-9)	Assessed if all items are relevant for the study population in small sample size (≤ 5)	NOT assessed if all items are relevant for the study population OR target population not involved

3	Was there an assessment of whether all items are relevant for the purpose of the measurement instrument? (discriminative, evaluative, and/or predictive)	Assessed if all items are relevant for the purpose of the application	Purpose of the instrument was not described but assumed	NOT assessed if all items are relevant for the purpose of the application	
4	Was there an assessment of whether all items together comprehensively reflect the construct to be measured?	Assessed if all items together comprehensively reflect the construct to be measured		No theoretical foundation of the construct and this was not taken into consideration	NOT assessed if all items together comprehensively reflect the construct to be measured
5	Were there any important flaws in the design or methods of the study?	No other important methodological flaws in the design or execution of the study		Other minor methodological flaws in the design or execution of the study	Other important methodological flaws in the design or execution of the study

Box E. Structural validity		excellent	good	fair	poor
1 Does the scale consist of effect indicators, i.e. is it based on a reflective model?					
<i>Design requirements</i>					
2 Was the percentage of missing items given?		Percentage of missing items described	Percentage of missing items NOT described		
3 Was there a description of how missing items were handled?		Described how missing items were handled	Not described but it can be deduced how missing items were handled	Not clear how missing items were handled	
4 Was the sample size included in the analysis adequate?		7* #items and ≥ 100	5* #items and ≥ 100 OR 5-7* #items but < 100	5* #items but < 100	$< 5^*$ #items
5 Were there any important flaws in the design or methods of the study?		No other important methodological flaws in the design or execution of the study		Other minor methodological flaws in the design or execution of the study (e.g. rotation method not described)	Other important methodological flaws in the design or execution of the study (e.g. inappropriate rotation method)

<i>Statistical methods</i>					
6 for CTT: Was exploratory or confirmatory factor analysis performed?		Exploratory or confirmatory factor analysis performed and type of factor analysis appropriate in view of existing information	Exploratory factor analysis performed while confirmatory would have been more appropriate		No exploratory or confirmatory factor analysis performed
7 for IRT: Were IRT tests for determining the (uni-) dimensionality of the items performed?		IRT test for determining (uni)dimensionality performed			IRT test for determining (uni)dimensionality NOT performed

Box F. Hypotheses testing		excellent	good	fair	Poor
<i>Design requirements</i>					
1 Was the percentage of missing items given?		Percentage of missing items described	Percentage of missing items NOT described		
2 Was there a description of how missing items were handled?		Described how missing items were handled	Not described but it can be deduced how missing items were handled	Not clear how missing items were handled	
3 Was the sample size included in the analysis adequate?		Adequate sample size (≥ 100 per analysis)	Good sample size (50-99 per analysis)	Moderate sample size (30-49 per analysis)	Small sample size (< 30 per analysis)

4	Were hypotheses regarding correlations or mean differences formulated a priori (i.e. before data collection)?	Multiple hypotheses formulated a priori	Minimal number of hypotheses formulate a priori	Hypotheses vague or not formulated but possible to deduce what was expected	Unclear what was expected
5	Was the expected direction of correlations or mean differences included in the hypotheses?	Expected direction of the correlations or differences stated	Expected direction of the correlations or differences NOT stated		
6	Was the expected absolute or relative magnitude of correlations or mean differences included in the hypotheses?	Expected magnitude of the correlations or differences stated	Expected magnitude of the correlations or differences NOT stated		
7	for convergent validity: Was an adequate description provided of the comparator instrument(s)?	Adequate description of the constructs measured by the comparator instrument(s)	Adequate description of most of the constructs measured by the comparator instrument(s)	Poor description of the constructs measured by the comparator instrument(s)	NO description of the constructs measured by the comparator instrument(s)
8	for convergent validity: Were the measurement properties of the comparator instrument(s) adequately described?	Adequate measurement properties of the comparator instrument(s) in a population similar to the study population	Adequate measurement properties of the comparator instrument(s) but not sure if these apply to the study population	Some information on measurement properties (or a reference to a study on measurement properties) of the comparator instrument(s) in any study population	No information on the measurement properties of the comparator instrument(s)

9	Were there any important flaws in the design or methods of the study?	No other important methodological flaws in the design or execution of the study		Other minor methodological flaws in the design or execution of the study (e.g. only data presented on a comparison with an instrument that measures another construct)	Other important methodological flaws in the design or execution of the study
	Statistical methods				
10	Were design and statistical methods adequate for the hypotheses to be tested?	Statistical methods applied appropriate	Assumable that statistical methods were appropriate, e.g. Pearson correlations applied, but distribution of scores or mean (SD) not presented	Statistical methods applied NOT optimal	Statistical methods applied NOT appropriate

Box G. Cross-cultural validity		excellent	good	fair	poor
<i>Design requirements</i>					
1	Was the percentage of missing items given?	Percentage of missing items described	Percentage of missing items NOT described		
2	Was there a description of how missing items were handled?	Described how missing items were handled	Not described but it can be deduced how missing items were handled	Not clear how missing items were handled	

3	Was the sample size included in the analysis adequate?	CTT: 7* #items and ≥100 IRT: ≥200 per group	CTT: 5* #items and ≥100 OR 5-7* #items but <100 IRT: ≥200 in 1 group and 100-199 in 1 group	CTT: 5* #items but <100 IRT: 100-199 per group	CTT: <5* #items IRT: <100 in 1 or both groups
4	Were both the original language in which the HR-PRO instrument was developed, and the language in which the HR-PRO instrument was translated described?	Both source language and target language described			Source language NOT known
5	Was the expertise of the people involved in the translation process adequately described? e.g. expertise in the disease(s) involved, expertise in the construct to be measured, expertise in both languages	Expertise of the translators described with respect to disease, construct, and language	Expertise of the translators with respect to disease or construct poor or not described	Expertise of the translators with respect to language not described	
6	Did the translators work independently from each other?	Translators worked independent	Assessable that the translators worked independent	Unclear whether translators worked independent	Translators worked NOT independent
7	Were items translated forward and backward?	Multiple forward and multiple backward translations	Multiple forward translations but one backward translation	One forward and one backward translation	Only a forward translation
8	Was there an adequate description of how differences between the original and translated versions were resolved?	Adequate description of how differences between translators were resolved	Poorly or NOT described how differences between translators were resolved		
9	Was the translation reviewed by a committee (e.g. original developers)?	Translation reviewed by a committee (involving other people than the translators, e.g. the original developers)	Translation NOT reviewed by (such) a committee		

10	Was the HR-PRO instrument pre-tested (e.g. cognitive interviews) to check interpretation, cultural relevance of the translation, and ease of comprehension?	Translated instrument pre-tested in the target population	Translated instrument pre-tested, but unclear if this was done in the target population	Translated instrument pre-tested, but NOT in the target population	Translated instrument NOT pre-tested
11	Was the sample used in the pre-test adequately described?	Sample used in the pre-test adequately described		Sample used in the pre-test NOT (adequately) described	
12	Were the samples similar for all characteristics except language and/or cultural background?	Shown that samples were similar for all characteristics except language /culture	Stated (but not shown) that samples were similar for all characteristics except language /culture	Unclear whether samples were similar for all characteristics except language /culture	Samples were NOT similar for all characteristics except language /culture
13	Were there any important flaws in the design or methods of the study?	No other important methodological flaws in the design or execution of the study		Other minor methodological flaws in the design or execution of the study	Other important methodological flaws in the design or execution of the study

<i>Statistical methods</i>			
14	for CTT: Was confirmatory factor analysis performed?	Multiple-group confirmatory factor analysis performed	Multiple-group confirmatory factor analysis NOT performed
15	for IRT: Was differential item function (DIF) between language groups assessed?	DIF between language groups assessed	DIF between language groups NOT assessed

Box B. Criterion validity		excellent	good	fair	poor
<i>Design requirements</i>					
1	Was the percentage of missing items given?	Percentage of missing items described	Percentage of missing items NOT described		
2	Was there a description of how missing items were handled?	Described how missing items were handled	Not described but it can be deduced how missing items were handled	Not clear how missing items were handled	
3	Was the sample size included in the analysis adequate?	Adequate sample size (≥ 100)	Good sample size (50-99)	Moderate sample size (30-49)	Small sample size (< 30)
4	Can the criterion used or employed be considered as a reasonable 'gold standard'?	Criterion used can be considered an adequate 'gold standard' (evidence provided)	No evidence provided, but assumable that the criterion used can be considered an adequate 'gold standard'	Unclear whether the criterion used can be considered an adequate 'gold standard'	Criterion used can NOT be considered an adequate 'gold standard'

5	Were there any important flaws in the design or methods of the study?	No other important methodological flaws in the design or execution of the study		Other minor methodological flaws in the design or execution of the study	Other important methodological flaws in the design or execution of the study
<i>Statistical methods</i>					
6	for continuous scores: Were correlations, or the area under the receiver operating curve calculated?	Correlations or AUC calculated			Correlations or AUC NOT calculated
7	for dichotomous scores: Were sensitivity and specificity determined?	Sensitivity and specificity calculated			Sensitivity and specificity NOT calculated

Box E. Responsiveness		excellent	good	fair	poor
<i>Design requirements</i>					
1	Was the percentage of missing items given?	Percentage of missing items described	Percentage of missing items NOT described		
2	Was there a description of how missing items were handled?	Described how missing items were handled	Not described but it can be deduced how missing items were handled	Not clear how missing items were handled	
3	Was the sample size included in the analysis adequate?	Adequate sample size (≥ 100)	Good sample size (50-99)	Moderate sample size (30-49)	Small sample size (< 30)
4	Was a longitudinal design with at least two measurement used?	Longitudinal design used			No longitudinal design used
5	Was the time interval stated?	Time interval adequately described			Time interval NOT described

6	If anything occurred in the interim period (e.g. intervention, other relevant events), was it adequately described?	Anything that occurred during the interim period (e.g. treatment) adequately described	Assumable what occurred during the interim period	Unclear or NOT described what occurred during the interim period
7	Was a proportion of the patients changed (i.e. improvement or deterioration)?	Part of the patients were changed (evidence provided)	NO evidence provided, but assumable that part of the patients were changed	Unclear if part of the patients were changed Patients were NOT changed
Design requirements for hypotheses testing				
For constructs for which a gold standard was not available:				
8	Were hypotheses about changes in scores formulated a priori (i.e. before data collection)?	Hypotheses formulated a priori		Hypotheses vague or not formulated but possible to deduce what was expected Unclear what was expected
9	Was the expected direction of correlations or mean differences of the change scores of HR-PRO instruments included in these hypotheses?	Expected direction of the correlations or differences stated	Expected direction of the correlations or differences NOT stated	
10	Were the expected absolute or relative magnitude of correlations or mean differences of the change scores of HR-PRO instruments included in these hypotheses?	Expected magnitude of the correlations or differences stated	Expected magnitude of the correlations or differences NOT stated	
11	Was an adequate description provided of the comparator instrument(s)?	Adequate description of the constructs measured by the comparator instrument(s)		Poor description of the constructs measured by the comparator instrument(s) NO description of the constructs measured by the comparator instrument(s)

12	Were the measurement properties of the comparator instrument(s) adequately described?	Adequate measurement properties of the comparator instrument(s) in a population similar to the study population	Adequate measurement properties of the comparator instrument(s) but not sure if these apply to the study population	Some information on measurement properties (or a reference to a study on measurement properties) of the comparator instrument(s) in any study population NO information on the measurement properties of the comparator instrument(s)
13	Were there any important flaws in the design or methods of the study?	No other important methodological flaws in the design or execution of the study		Other minor methodological flaws in the design or execution of the study (e.g. only data presented on a comparison with an instrument that measures another construct) Other important methodological flaws in the design or execution of the study
Statistical methods				
14	Were design and statistical methods adequate for the hypotheses to be tested?	Statistical methods applied appropriate		Statistical methods applied NOT optimal Statistical methods applied NOT appropriate

Design requirement for comparison to a gold standard			
For constructs for which a gold standard was available:			
15	Can the criterion for change be considered as a reasonable gold standard?	Criterion used can be considered an adequate 'gold standard' (evidence provided)	No evidence provided, but assumable that the criterion used can be considered an adequate 'gold standard'
16	Were there any important flaws in the design or methods of the study?	Unclear whether the criterion used can be considered an adequate 'gold standard'	Criterion used can NOT be considered an adequate 'gold standard'
Statistical methods		No other important methodological flaws in the design or execution of the study	Other minor methodological flaws in the design or execution of the study
17	for continuous scores: Were correlations between change scores, or the area under the Receiver Operator Curve (ROC) curve calculated?	Other important methodological flaws in the design or execution of the study	Other important methodological flaws in the design or execution of the study
18	for dichotomous scales: Were sensitivity and specificity (changed versus not changed) determined?	Correlations or Area under the ROC Curve (AUC) calculated	Correlations or AUC NOT calculated
		Sensitivity and specificity calculated	Sensitivity and specificity NOT calculated

Interpretability

We recommend to use the Interpretability box to extract all information on the interpretability issues described in this box of the instruments under study from the included articles.

Box Interpretability	
Percentage of missing items	
Description of how missing items were handled	
Distribution of the (total) scores	
Percentage of the respondents who had the lowest possible (total) score	
Percentage of the respondents who had the highest possible (total) score	
Scores and change scores (i.e. means and SDs) for relevant (sub) groups, e.g. for normative groups, subgroups of patients, or the general population	
Minimal Important Change (MIC) or Minimal Important Difference (MID)	

Generalizability

We recommend to use the Generalizability box to extract data on the characteristics of the study populations and sampling procedures of the included studies.

Box Generalizability	
Median or mean age (with standard deviation or range)	
Distribution of sex	
Important disease characteristics (e.g. severity, status, duration) and description of treatment	
Setting(s) in which the study was conducted (e.g. general population, primary care or hospital/rehabilitation care)	
Countries in which the study was conducted	
Language in which the HR-PHO instrument was evaluated	
Method used to select patients (e.g. convenience, consecutive, or random)	
Percentage of missing responses (response rate)	

Appendix B – Letter of HRA Approval

Dr William Mandy
Research Department of Clinical, Educational & Healthy
Psychology
1-19 Torrington Place
London
WC1E 7HP

21 December 2017

Dear Dr Mandy

Letter of HRA Approval

Study title: Social Skills in Autistic Teenagers
IRAS project ID: 233394
REC reference: 17/LO/2055
Sponsor: University College London

I am pleased to confirm that HRA Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from the [HRA website](#).

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the [HRA website](#), and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the [HRA website](#).

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found through [IRAS](#).

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

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

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procedure. If you wish to make your views known please use the feedback form available on the [HRA website](#).

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details on the [HRA website](#).

Your IRAS project ID is 233394. Please quote this on all correspondence.

Yours sincerely

Miss Helen Penistone
Assessor

Email: hra.approval@nhs.net

Copy to: *Nikkayla Dixon (sponsor)*
Miriam Bindman, Great Ormond Street Hospital Trust Social Communication
Disorders Clinic (lead NHS R&D)

Appendix A - List of Documents

The final document set assessed and approved by HRA Approval is listed below.

Document	Version	Date
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [UCL Insurance Confirmation]	1	30 August 2017
HRA Schedule of Events	1	22 November 2017
HRA Statement of Activities	1	22 November 2017
IRAS Application Form [IRAS_Form_10112017]		10 November 2017
Letter from funder [Funding Letter]	1	06 October 2017
Letter from sponsor [UCL Email of Sponsorship Confirmation]	1	03 November 2017
Letters of invitation to participant [Advertisement ASD]	2	19 December 2017
Letters of invitation to participant [Advert/Letter of Invitation for Typically Developing Participants]	2	19 December 2017
Non-validated questionnaire [Self-Report Camouflaging Questionnaire]	1	27 October 2017
Non-validated questionnaire [Parent-Report Camouflaging Questionnaire]	1	27 October 2017
Non-validated questionnaire [Social Impressions Task]	1	27 October 2017
Participant consent form [Consent Form Autistic Participants]	5	19 December 2017
Participant consent form [Consent Form Typically Developing Participants]	4	19 December 2017
Participant consent form [Consent Form Parents of Autistic Participants]	5	19 December 2017
Participant consent form [Consent Form Parents of Typically Developing Participants]	4	19 December 2017
Participant consent form [Assent Form Autistic Participants 13-15 Years]	4	19 December 2017
Participant consent form [Assent Form Typically Developing Participants 13-15 Years]	4	19 December 2017
Participant information sheet (PIS) [PIS Autistic Participants 16-19 years]	6	19 December 2017
Participant information sheet (PIS) [PIS Typically Developing Participants 16-19 Years]	5	19 December 2017
Participant information sheet (PIS) [PIS Parents of Autistic Participants Recruited via NHS]	6	19 December 2017
Participant information sheet (PIS) [PIS Parents of Autistic Participants Recruited outside NHS]	5	19 December 2017
Participant information sheet (PIS) [PIS Parents of Typically Developing Participants]	5	19 December 2017
Participant information sheet (PIS) [PIS Autistic Participants 13-15 Years]	4	19 December 2017
Participant information sheet (PIS) [PIS Typically Developing Participants 13-15 Years]	4	19 December 2017
Referee's report or other scientific critique report [Peer Review]	1	14 September 2017
Research protocol or project proposal [SSAT Protocol]	4	27 October 2017
Response to Request for Further Information [Email from Laura Hull]		19 December 2017
Summary CV for Chief Investigator (CI) [William Mandy CV]	1	25 October 2017
Summary CV for student [Laura Hull CV]	1	24 October 2017

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Summary CV for supervisor (student research) [William Mandy CV]	1	25 October 2017
Validated questionnaire [Autism Quotient]	1	15 November 2017
Validated questionnaire [Friendship Questionnaire]	1	15 November 2017
Validated questionnaire [Strange Stories]	1	15 November 2017
Validated questionnaire [ADOS Module 4 Response Booklet]		
Validated questionnaire [BRIEF Parent Form]		
Validated questionnaire [SRS Autoscore Form]		

Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

For information on how the sponsor should be working with participating NHS organisations in England, please refer to the, *participating NHS organisations, capacity and capability and Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria) sections in this appendix.*

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Name: Nikkayla Dixon
 Tel: 0203 447 7430 Ext. 77430
 Email: Nikkayla.Dixon@uclh.nhs.uk

HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	Part C of the IRAS form has been correctly completed.
2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	The sponsor intends that the Statement of Activities will be used to form an agreement with participating NHS organisations. No additional agreement is expected.
4.2	Insurance/indemnity arrangements assessed	Yes	Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the

Section	HRA Assessment Criteria	Compliant with Standards	Comments
			activities expected of them for this research study
4.3	Financial arrangements assessed	Yes	As per the Statement of Activities, there will be no funding available to sites.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	<p>Data will be stored for 20 years after the end of the study.</p> <p>The document with participants' names and IDs will be stored on an encrypted hard drive, locked in a filing cabinet in Laura Hull's office (only accessible by Laura Hull).</p> <p>Access to medical records, for the purpose of confirming autism diagnosis and any previous assessments of IQ, has been made explicit in the information sheets.</p> <p>No identifiable data will be shared with participants' clinicians, except in group, anonymised format.</p>
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	No comments
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

Participating NHS Organisations in England

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

There will be one site type where all site activities will be undertaken as per the study protocol and supporting documents. If participants prefer, they will complete the study activities away from the NHS site.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. For NIHR CRN Portfolio studies, the Local LCRN contact should also be copied into this correspondence. For further guidance on working with participating NHS organisations please see the HRA website.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England which are not provided in IRAS or on the HRA website, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra_approval@nhs.net. The HRA will work with these organisations to achieve a consistent approach to information provision.

Confirmation of Capacity and Capability

This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.

Participating NHS organisations in England will **be expected to formally confirm their capacity and capability to host this research.**

- Following issue of this letter, participating NHS organisations in England may now confirm to the sponsor their capacity and capability to host this research, when ready to do so. How capacity and capability will be confirmed is detailed in the *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* section of this appendix.
- The [Assessing, Arranging, and Confirming](#) document on the HRA website provides further information for the sponsor and NHS organisations on assessing, arranging and confirming capacity and capability.

Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).

There will be a local collaborator at sites to facilitate access to site and practical arrangements.

GCP training is not a generic training expectation, in line with the [HRA/MHRA statement on training](#)

[expectations.](#)

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken

Where arrangements are not already in place, it is expected that externally employed researchers accessing site to carry out research activities would obtain a letter of access based on enhanced DBS checks and occupational health clearance.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England to aid study set-up.

The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

Appendix C – Recruitment Advertisement

Social Skills in Autistic Teenagers (SSAT) study

Researchers at University College London (UCL) are looking for **adolescents aged 13-19** with a diagnosis of **autism spectrum disorder (ASD)** and their parents to take part in a study of social skills.

The study involves completing questionnaires and having a video-recorded interaction with a researcher. The study will take around **two hours** to complete, and can take place at your home or at UCL.

Travel expenses (£10 per adult, £5 per child) will be reimbursed for those taking part. Participants will also be entered into a prize draw to win the following high street vouchers:-

- 1 x £50
- 2 x £25
- 3 x £15
- 10 x £10

For more information, please contact **Benjamin Hannon** at **b.hannon.17@ucl.ac.uk** or **07711227277**.

This study has been approved by the UCL/UCLH Joint Research Office, Great Ormond Street Hospital Trust, Central London Community Healthcare NHS Trust, and the Whittington Hospital NHS Trust.

Appendix D – Participant Information Sheets

Participant Information Sheet (ASD Parent/Caregiver, recruited outside NHS)

Title of Project: Social Skills in Autistic Teenagers (SSAT)

Researchers: Dr William Mandy, Laura Hull

Research Department of Clinical, Educational & Health Psychology,
University College London

WC1E 6BT

w.mandy@ucl.ac.uk

laura.hull.14@ucl.ac.uk

020 7679 592

020 7679 5365

Invitation to take part

You and your child are invited to take part in a study looking at social skills in teenagers with autism spectrum conditions. This is a student study being completed as part of Laura Hull's PhD. The study is run by researchers from University College London (UCL) in collaboration with Great Ormond Street Hospital Trust, Central London Community Healthcare NHS Trust, and the Whittington Hospital NHS Trust.

Before you decide to take part in this study it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Your child has been given their own copy of this information sheet; please discuss the study with them. Ask the researcher (Laura) if you have any questions or if anything is unclear. Take time to decide whether or not you and your child wish to take part.

Aims of the study

This study aims to examine autistic teenagers' social skills and the impressions that others have of them. We will compare multiple different measures of social skills, and will also look at the influence of gender, age, and other factors on their social abilities.

Why have my child and I been approached?

You have received this information sheet because you expressed interest in this study through social media, or by contacting one of the researchers after seeing an advert for this study.

If you are the parent or caregiver of an autistic individual aged between 13 and 19 years, whom you live with or interact with at least weekly, you are eligible to take part.

If your child has a diagnosis of an autism spectrum disorder (ASD), is aged between 13 and 19 years, and does not have a learning disability, they are eligible to take part.

Do I have to take part?

Taking part in this study is entirely voluntary. You do not have to give a reason for not taking part, and there will be no consequences for your child's medical treatment or your legal rights for not taking part in this study.

What will happen to me if I take part?

The study will involve your child completing some behavioural tasks and both you and your child completing some questionnaires. The study will take place at your home, at UCL in private testing rooms, or at your local clinic depending on your preference. The entire testing session will take approximately two hours, including a break.

What will my child and I have to do?

The researcher may come to your home, or you and your child will be invited to come to testing rooms in UCL or at your local clinic, depending on your preference, at a time that suits you. The researcher will go through this information sheet with you again, and you will be asked to sign a consent form agreeing that you and your child will take part. If your child is aged 13-15, you will be asked to consent on their behalf and they will complete an informed assent form. If your child is aged 16-19, they will complete their own consent form.

Your child will be asked to complete a diagnostic assessment which they may have completed when they were first assessed for autism, which will be audio and video recorded. This will take approximately 40 minutes, and you will be asked to remain in a waiting room and complete some questionnaires about your child's social abilities and the way they think. Your child will then be asked to complete a brief behavioural task which involves having a conversation with the experimenter, which will be audio and video recorded. This will take approximately 10 minutes.

You and your child can then have a break for 20 minutes, and refreshments will be provided. After the break your child will be asked to complete some questionnaires with the experimenter, including an assessment of their intellectual ability if this has not been previously recorded. This will take approximately 30-40 minutes, and you can be in the room as well if you and your child wish.

You and your child do not have to take part in any part of this study if you do not wish to. If at any point you wish to withdraw from or pause the study, you can do so by telling the researcher or experimenter that you wish to stop. You do not have to give a reason for pausing or withdrawing, and there will be no repercussions for withdrawing. If you have travelled to the study site, your travel expenses will still be reimbursed even if you withdraw during or after the testing session.

Disadvantages of taking part

There are no predicted disadvantages of taking part for you or your child. If at any point during the study you or your child become tired, distressed, or wish to take a

break, you can pause the study by telling the experimenter you wish to do so. You do not have to give a reason.

Benefits of taking part

The assessments your child will undergo do not represent a full clinical assessment, and cannot be used as an assessment for their abilities and/or difficulties. However, once the results from a large number of respondents are analysed and published, we hope your responses will improve the understanding of autism researchers, clinicians, and educators, as well as the broader community, about autistic teenagers' social skills. If you are interested, we can send you a summary of our findings when the study is completed.

Confidentiality

Your child's ADOS assessment and behavioural social skills task will be video and audio taped to allow for standardised scoring. All other data will be stored securely and any personally identifiable information will be removed. When the study finishes in September 2019, we will keep your data in an anonymous format unless you ask us to delete it

Hard copies of all responses will be transferred to electronic format and will be stored securely until the completion of the study (September 2019), at which point they will be destroyed. All electronic data will be stored on a secure internet server and will only be accessible to the researchers and clinicians involved with this study. The findings of this study may be published in academic journals and/or presented at conferences. All responses will be presented in group format and no individual responses will be reported. Your data will be stored in accordance with the Data Protection Act 1998.

If you agree for your and your child's responses to be used in future research, we will store your data securely and anonymously for 20 years. If you do not wish for your data to be used in future research, we will destroy your and your child's responses, including the audio and video recordings, once the study ends.

Reimbursement

No reimbursement is offered for this study. However, any travel expenses incurred while travelling to and from the study site within London will be reimbursed, provided full receipts are given to the researchers. Your travel expenses will be reimbursed for travel within London, up to £10 for adults and £5 for children (aged 13-15). You will need to email travel receipts to the researchers (laura.hull.14@ucl.ac.uk).

Withdrawal

You or your child will be able to withdraw from this study at any point by asking the experimenter to stop the study. If you withdraw from the study, the data you have provided so far will be retained unless you request for it to be removed from the study. You can also withdraw your own and your child's data from the study at any point until June 2019, by contacting the researchers and asking for your data to be

removed. You do not need to provide an explanation for your withdrawal, and there will be no repercussions for withdrawing.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak with Laura Hull (Study Principal Investigator) on 02076 795 365, who will do her best to answer your questions. If you remain unhappy and wish to complain formally about any aspect of the way you have been approached or treated during the course of this study, UCL complaints mechanisms are also available to you. In the unlikely event that you are harmed by taking part in this study, compensation may be available.

If you suspect that the harm is the result of the Sponsor's (University College London) negligence then you may be able to claim compensation. Please make the claim in writing to Dr William Mandy who is the Chief Investigator for the research and is based at University College London. The Chief Investigator will then pass the claim to the Sponsor's Insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

Who has reviewed the study?

All proposals for research using human subjects are reviewed by an Ethics Committee before they can proceed. This proposal was reviewed by University College London Research Ethics Committee.

Who is organising and funding the study?

This study is being funded by University College London, who are sponsoring the study.

What will happen to the results of the study?

When the study has finished we will present our findings to other researchers and doctors, and we will put the results in academic magazines. The results will be written up as part of Laura Hull's PhD thesis. The results might also be discussed at conferences, although we will only refer to groups so no individual responses will be discussed. All results will be anonymous, which means that you will not be able to be identified from them. If you are interested in finding out more about the results of the study, tell the researcher and we can send you a summary when we have finished analysis.

Who to contact

If you have any further questions about the study, we are happy to discuss these with you. It is important that you and your child fully understand what you are being asked to do before you begin the study. Please contact Laura Hull (laura.hull.14@ucl.ac.uk; 020 7679 5365) or Dr William Mandy (w.mandy@ucl.ac.uk; 020 7679 1675) for more information, or if you have any questions or concerns about this study.

If you and your child are willing to take part in this study, please contact the researchers to and confirm your interest. A testing time and location will be arranged to suit you. Agreeing to take part does not mean you have to do so; you can still withdraw at any time and do not have to give a reason for withdrawing.

Participant Information Sheet (ASD Parent/Caregiver, recruited through NHS)

Title of Project: Social Skills in Autistic Teenagers (SSAT)

Researchers: Dr William Mandy, Laura Hull

Research Department of Clinical, Educational & Health Psychology,
University College London

WC1E 6BT

w.mandy@ucl.ac.uk

laura.hull.14@ucl.ac.uk

020 7679 592

020 7679 5365

Invitation to take part

You and your child are invited to take part in a study looking at social skills in teenagers with autism spectrum conditions. This is a student study being completed as part of Laura Hull's PhD. The study is run by researchers from University College London (UCL) in collaboration with Great Ormond Street Hospital Trust, Central London Community Healthcare NHS Trust, and the Whittington Hospital NHS Trust.

Before you decide to take part in this study it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Your child has been given their own copy of this information sheet; please discuss the study with them. Ask the researcher (Laura) if you have any questions or if anything is unclear. Take time to decide whether or not you and your child wish to take part.

Aims of the study

This study aims to examine autistic teenagers' social skills and the impressions that others have of them. We will compare multiple different measures of social skills, and will also look at the influence of gender, age, and other factors on their social abilities.

Why have my child and I been approached?

You have received this information sheet because you expressed interest in this study when you were contacted by a member of the healthcare team at your local clinic, and you previously agreed to be contacted to take part in research.

If you are the parent or caregiver of an autistic individual aged between 13 and 19 years, whom you live with or interact with at least weekly, you are eligible to take part.

If your child has a diagnosis of an autism spectrum disorder (ASD), is aged between 13 and 19 years, and does not have a learning disability, they are eligible to take part.

Do I have to take part?

Taking part in this study is entirely voluntary. You do not have to give a reason for not taking part, and there will be no consequences for your child's medical treatment or your legal rights for not taking part in this study.

What will happen to me if I take part?

The study will involve your child completing some behavioural tasks and both you and your child completing some questionnaires. The study will take place at your home, at UCL in private testing rooms, or at your local clinic depending on your preference. The entire testing session will take approximately two hours, including a break.

What will my child and I have to do?

The researcher may come to your home, or you and your child will be invited to come to testing rooms in UCL or at your local clinic, depending on your preference, at a time that suits you. The researcher will go through this information sheet with you again, and you will be asked to sign a consent form agreeing that you and your child will take part. If your child is aged 13-15, you will be asked to consent on their behalf and they will complete an informed assent form. If your child is aged 16-19, they will complete their own consent form.

Your child will be asked to complete a diagnostic assessment which they may have completed when they were first assessed for autism, which will be audio and video recorded. This will take approximately 40 minutes, and you will be asked to remain in a waiting room and complete some questionnaires about your child's social abilities and the way they think. Your child will then be asked to complete a brief behavioural task which involves having a conversation with the experimenter, which will be audio and video recorded. This will take approximately 10 minutes.

You and your child can then have a break for 20 minutes, and refreshments will be provided. After the break your child will be asked to complete some questionnaires with the experimenter, including an assessment of their intellectual ability if this has not been previously recorded. This will take approximately 30-40 minutes, and you can be in the room as well if you and your child wish.

You and your child do not have to take part in any part of this study if you do not wish to. If at any point you wish to withdraw from or pause the study, you can do so by telling the researcher or experimenter that you wish to stop. You do not have to give a reason for pausing or withdrawing, and there will be no repercussions for withdrawing. If you have travelled to the study site, your travel expenses will still be reimbursed even if you withdraw during or after the testing session.

Disadvantages of taking part

There are no predicted disadvantages of taking part for you or your child. If at any point during the study you or your child become tired, distressed, or wish to take a break, you can pause the study by telling the experimenter you wish to do so. You do not have to give a reason.

Benefits of taking part

The assessments your child will undergo do not represent a full clinical assessment, and cannot be used as an assessment for their abilities and/or difficulties. However, once the results from a large number of respondents are analysed and published, we hope your responses will improve the understanding of autism researchers, clinicians, and educators, as well as the broader community, about autistic teenagers' social skills. If you are interested, we can send you a summary of our findings when the study is completed.

Confidentiality

Your child's ADOS assessment and behavioural social skills task will be video and audio taped to allow for standardised scoring. All other data will be stored securely and any personally identifiable information will be removed. When the study finishes in September 2019, we will keep your data in an anonymous format unless you ask us to delete it.

Hard copies of all responses will be transferred to electronic format and will be stored securely until the completion of the study (September 2019), at which point they will be destroyed. All electronic data will be stored on a secure internet server and will only be accessible to the researchers and clinicians involved with this study. The findings of this study may be published in academic journals and/or presented at conferences. All responses will be presented in group format and no individual responses will be reported. Your data will be stored in accordance with the Data Protection Act 1998.

If you agree for your and your child's responses to be used in future research, we will store your data securely and anonymously for 20 years. If you do not wish for your data to be used in future research, we will destroy your and your child's responses, including the audio and video recordings, once the study ends.

Reimbursement

No reimbursement is offered for this study. However, any travel expenses incurred while travelling to and from the study site will be reimbursed, provided full receipts are given to the researchers. Your travel expenses will be reimbursed for travel within London, up to £10 for adults and £5 for children (aged 13-15). You will need to email travel receipts to the researchers (laura.hull.14@ucl.ac.uk).

Withdrawal

You or your child will be able to withdraw from this study at any point by asking the experimenter to stop the study. If you withdraw from the study, the data you have provided so far will be retained unless you request for it to be removed from the study. You can also withdraw your own and your child's data from the study at any point until June 2019, by contacting the researchers and asking for your data to be removed. You do not need to provide an explanation for your withdrawal, and there will be no repercussions for withdrawing.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak with Laura Hull (Study Principal Investigator) on 02076 795 365, who will do her best to answer your questions. If you remain unhappy and wish to complain formally about any aspect of the way you have been approached or treated during the course of this study, UCL complaints mechanisms or National Health Service complaints mechanisms are also available to you, such as the Patient Advice Liaison Services (PALS) at [insert site name]. They can be contacted by [insert PALS details for site]. In the unlikely event that you are harmed by taking part in this study, compensation may be available.

If you suspect that the harm is the result of the Sponsor's (University College London) or the hospital's negligence then you may be able to claim compensation. After discussing with your research doctor, please make the claim in writing to Dr William Mandy who is the Chief Investigator for the research and is based at University College London. The Chief Investigator will then pass the claim to the Sponsor's Insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

Who has reviewed the study?

All proposals for research using human subjects are reviewed by an Ethics Committee before they can proceed. This proposal was reviewed by University College London Research Ethics Committee.

Who is organising and funding the study?

This study is being funded by University College London, who are sponsoring the study.

What will happen to the results of the study?

When the study has finished we will present our findings to other researchers and doctors, and we will put the results in academic magazines. The results will be written up as part of Laura Hull's PhD thesis. The results might also be discussed at conferences, although we will only refer to groups so no individual responses will be discussed. All results will be anonymous, which means that you will not be able to be identified from them. If you are interested in finding out more about the results of the study, tell the researcher and we can send you a summary when we have finished analysis.

Who to contact

If you have any further questions about the study, we are happy to discuss these with you. It is important that you and your child fully understand what you are being asked to do before you begin the study. Please contact Laura Hull (laura.hull.14@ucl.ac.uk; 020 7679 5365) or Dr William Mandy (w.mandy@ucl.ac.uk; 020 7679 592) for more information, or if you have any questions or concerns about this study.

If you and your child are willing to take part in this study, please contact your local clinic, who contacted you about this study, and confirm your interest. You will then be contacted by the researchers to arrange a testing time and location to suit you. Agreeing to take part does not mean you have to do so; you can still withdraw at any time and do not have to give a reason for withdrawing.

Participant Information Sheet (ASD Adolescent, 13-15)

Study Title: Social Skills in Autistic Teenagers (SSAT)

Key Researchers: Dr William Mandy, Laura Hull

Part 1 – to give you first thoughts about the project

a) Invitation to take part

We would like you to help us with our research study, which is part of Laura Hull's PhD research. Please read this information carefully and talk to your mum, dad or carer about the study. Ask the researcher (Laura) if there is anything that is not clear or if you want to know more. Take time to decide if you want to take part. It is up to you if you want to do this. If you don't then that's fine, nothing will change in the care you receive from your clinical care team.

b) Why are we doing this research?

We want to try and find out more about the social skills that teenagers with and without autism have, and the factors that influence social skills, including age and gender.

c) Why have I been asked to take part?

You have been chosen because you have a diagnosis of an autism spectrum disorder (ASD). We are asking 146 young people to take part in total. Some of those do have an ASD diagnosis, others don't.

You or your parent/carer have contacted the researchers to find out more about this study. If you are willing to take part in the study we will arrange a time to visit you at your home, or for you to come to a testing room at University College London (UCL) or your local clinic. This testing session will involve gaining written consent from you and your parent or carer, completing some behavioural tasks, and filling in some questionnaires with the experimenter. This is the only time you will have to take part in the study.

d) Do I have to take part?

No! It is entirely up to you. If you do decide to take part:

- You will be asked to sign a form to say that you agree to take part (an assent form)
- You will be given this information sheet and a copy of your signed assent form to keep.

You are free to stop taking part at any time during the research without giving a reason. If you decide to stop, this will not affect the care you receive from your clinical care team.



e) What will happen to me if I take part?

The researcher may come to your home, or you and your parent/caregiver will be invited to come to activity rooms in UCL or at your local clinic, whichever you prefer, at a time that suits you. If you do travel to take part in the study, your travel expenses within London will be reimbursed.

On the next page is a timeline of what will happen during the study. If at any point you want to take a break, just tell the researcher and they can pause the study.

1.



5 minutes

1. The researcher will come to your house, or you will arrive at UCL or your local clinic with your parent/caregiver. The researcher will explain what the study involves again, and ask your consent to take part in the study. You will be asked to sign a piece of paper saying that you consent to take part.

2.



5 minutes

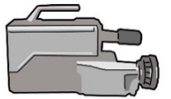
2. Meet the researcher and go to the activity room. Your parent/caregiver will stay in the waiting room and complete some questionnaires.

3.



40 minutes

3. Behavioural assessment with the researcher: Talk about your interests and experiences, look at some books and objects. This will be video recorded.

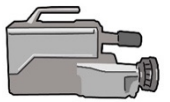


4.



10 minutes

4. Behavioural assessment with the researcher: Have a conversation about a holiday you recently went on. This will be video recorded.



5.



20 minutes

5. Have a break! You will go back to your parent/caregiver in the waiting room and have something to drink and eat.

6.



5 minutes

6. Go back to the activity room. Your parent/caregiver can come too if you would like them to.

7.



40 minutes

7. Complete some questionnaires about your social skills and how you think with the researcher.

8.



5 minutes

8. All finished! You can ask the researcher any more questions you have about the study, and then the study is over.

f) Will the study help me?

No, but the information we get will help us understand more about social behaviours in young people with and without autism, and might improve diagnosis and services for autistic people.

g) What happens when the research study stops?

We will collect all the information together and use this to describe some of factors which may affect young people's social skills. If you are happy for us to use your responses in future research, we will store your responses safely and anonymously – meaning no one will be able to know that you took part or what your responses were. If you don't want us to use your data in the future, we will delete the audio and video recordings of your data.

h) Contact for further information

If you would like any further information about this study you could contact:

Name: Laura Hull

Designation: PhD Student

University College London

Tel: 02076 795365

Email: laura.hull.14@ucl.ac.uk



Thank you for reading so far - if you are still interested, please go to Part 2:

Part 2 - more detail – information you need to know if you still want to take part.

a) What if I don't want to do the research anymore?

Just tell your mum, dad, carer, or the experimenter at any time. You don't have to give a reason for wanting to stop. They will not be cross with you. You will still have the same care from your clinical team.

If you want to take a break at any point during the study, you can do so by telling the experimenter. You do not have to give a reason and you can stop for as long as you want.

b) What if there is a problem or something goes wrong?

Tell us if there is a problem and we will try and sort it out straight away. You and your mum, dad or carer can contact the project co-ordinator:

Dr William Mandy

Senior Lecturer

University College London

w.mandy@ucl.ac.uk

020 7679 1675

c) Will anyone else know I'm doing this?

The people in our research team will know you are taking part. The people in your clinical care team may also know.

All information that is collected about you during the research will be kept strictly confidential. You will be given a number which will be used instead of your name.

All information about you will have your name and address removed so that you cannot be recognised from it. Once the study is complete all information will be kept in an anonymous format for 20 years. No one will be able to tell that you took part in the study or what your responses were.

d) What will happen to the results of the research study?

When the study has finished we will present our findings to other researchers and doctors, and we will put the results in academic magazines. The results will be written up as part of Laura Hull's PhD thesis. The results might also be discussed at conferences, although we will only refer to groups so no individual responses will be discussed. All results will be anonymous, which means that you will not be able to be identified from them. If you are interested in finding out more about the results of the study, tell the researcher and we can send you a summary when we have finished analysis.

e) Who is organising and funding the research?

Researchers at University College London are organising this study. They will not get any extra money for doing this research.

The research is being paid for by University College London, who are sponsoring this study.

f) Who has checked the study?

Before any research goes ahead it has to be checked by a Research Ethics Committee. This is a group of people who make sure that the research is OK to do. This study has been looked at by the University College London Research Ethics Committee.

g) What next?

Please read through this information sheet with your parent/caregiver. If you have any further questions about the study, we are happy to discuss these with you: email Laura at laura.hull.14@ucl.ac.uk.

Once you and your parent/caregiver are happy to take part in the study and have had all your questions answered, we will contact your parent/caregiver to arrange a time and location for you to come and complete the study. Agreeing to take part does not mean you have to do so; you can still stop at any time and do not have to give a reason for stopping.

What to remember:

- The study will take place in a private room. Only the researcher and your parent/caregiver (if you want them there) will be able to hear or see your responses while you give them.
- The study will take around two hours, and you can take as many breaks as you need if you get overwhelmed or for any other reason.
- You don't have to participate if you want to. Nothing bad will happen to you if you change your mind.
- When the study is completed you can receive a summary of all the findings. No one will be able to know that you took part or what your responses were from this summary.
- Your privacy will be respected. Only the researchers and your clinicians will ever have access to your responses.
- We are very grateful to you for helping us to learn more about autistic teenagers' social skills, so that we can help other people to understand as well.

Thank you for taking the time to read this – please ask any questions if you need to.

Participant Information Sheet (ASD Adolescent, 16-19)

Title of Project: Social Skills in Autistic Teenagers (SSAT)

Key Researchers: Dr William Mandy, Laura Hull

Invitation to take part

You are invited to take part in a study looking at social skills in young people with a diagnosis of autism spectrum conditions. This is a student study being completed as part of Laura Hull's PhD. The study is run by researchers from University College London (UCL) in collaboration with Great Ormond Street Hospital Trust, Central London Community Healthcare NHS Trust, and the Whittington Hospital NHS Trust.

Before you decide to take part in this study it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Your parent/caregiver has been given their own copy of this information sheet; please discuss the study with them. Ask the researcher (Laura) if you have any questions or if anything is unclear. Take time to decide whether or not you wish to take part.

Aims of the study

This study aims to examine autistic and non-autistic teenagers' social skills and some of the factors which may affect these social skills, including an individual's age and gender.

Why have I been approached?

You have received this information sheet because you or your parent/caregiver expressed interest in this study when you were contacted by a member of the healthcare team at your local clinic. Alternatively, your parent/caregiver might have seen an advert for this study and contacted the researchers.

If you have a diagnosis of an autism spectrum disorder (ASD), are aged between 13 and 19 years, and do not have a learning disability, you are eligible to take part.

Do I have to take part?

Taking part in this study is entirely voluntary. You do not have to give a reason for not taking part, and there will be no consequences for your medical treatment or your legal rights for not taking part in this study.

What will I have to do?

The researcher may come to your home, or you and your parent/caregiver will be invited to come to activity rooms in UCL or at your local clinic, whichever you prefer, at a time that

suits you. The researcher will go through this information sheet with you again and you will be asked to sign a form saying that you consent to take part.

The study will involve you completing some behavioural tasks and both you and your parent/caregiver completing some questionnaires. The entire testing session will take around two hours, including a break.

Below is a timeline of what will happen during the study. If at any point you want to take a break, just tell the researcher and they can pause the study.

9.



5 minutes

1. The researcher will come to your house, or you will arrive at UCL or your local clinic with your parent/caregiver. The researcher will explain what the study involves again, and ask your consent to take part in the study. You will be asked to sign a piece of paper saying that you consent to take part.

10.



5 minutes

2. Meet the researcher and go to the activity room. Your parent/caregiver will stay in the waiting room and complete some questionnaires.

11.



40 minutes

3. Behavioural assessment with the researcher: Talk about your interests and experiences, look at some books and objects. This will be video recorded.

12.



10 minutes

4. Behavioural assessment with the researcher: Have a conversation about a holiday you recently went on. This will be audio and video recorded.

13.



20 minutes

5. Have a break! You will go back to your parent/caregiver in the waiting room and have something to drink and eat.

14.



5 minutes

6. Go back to the activity room. Your parent/caregiver can come too if you would like them to.

15.



40 minutes

7. Complete some questionnaires about your social skills and how you think with the researcher.

16.



5 minutes

8. All finished! You can ask the researcher any more questions you have about the study, and then the study is over.

You do not have to take part in any part of this study if you do not wish to. If at any point you wish to stop or pause the study, you can do so by telling the researcher that you wish to stop. You do not have to give a reason for pausing or stopping, and nothing bad will happen to you because you chose to stop the study.

Disadvantages of taking part

There are no predicted disadvantages of taking part. If at any point during the study you feel tired, stressed, or want to take a break (for example to use the toilet), you can pause the study by telling the researcher you wish to do so. You do not have to give a reason for pausing the study.

Benefits of taking part

We will not be able to use your responses to tell you anything about you as an individual. However, we hope that by combining the responses of many teenagers, we can learn more about autistic teenagers' social skills and share this information with autistic people, their families, schools, and the wider community. If you are interested in the results of the study we can send you a summary once the study is complete.

Confidentiality

Some of the behavioural assessments will be video recorded so that other researchers can study them carefully later on. Only researchers working on this study will know that you were involved and what your answers were before entering the information into our database.

After the information is entered, no one will know what your answers were, except the researchers and the clinicians at your local clinic.

When the study has finished in September 2019, we will keep your data in an anonymous format unless you ask us to delete it. Other students and researchers may use your data in future research, but it will be anonymous; they will not be able to identify you from your data. When we describe the results of the study, your responses will be presented as part of a group and it will not be possible for anyone to identify you or your responses from these results.

If you agree for your responses to be used in future research, we will store your data securely and anonymously. If you do not wish for your data to be used in future research, we will destroy your responses, including the audio and video recordings, once the study ends.

Reimbursement

No reimbursement is offered for this study. However, any travel expenses incurred while travelling to and from the study site will be reimbursed, provided full receipts are given to the researchers. Your travel expenses will be reimbursed for travel within London, up to £10 for adults and £5 for children (aged 13-15). You will need to email travel receipts to the researchers (laura.hull.14@ucl.ac.uk).

Withdrawal

You can stop taking part in this study at any point by asking the researcher to stop. After you have finished the study, you can ask for your data to be removed at any point up until June 2019. You do not have to give a reason for stopping the study or for asking for your data to be removed.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak with Laura Hull (Study Principal Investigator) on 02076 795 365 or laura.hull.14@ucl.ac.uk, who will do her best to answer your questions. If you remain unhappy and wish to complain formally about any aspect of the way you have been approached or treated during the course of this study, UCL complaints mechanisms or National Health Service complaints mechanisms are also available to you. In the unlikely event that you are harmed by taking part in this study, compensation may be available.

If you suspect that the harm is the result of the Sponsor's (University College London) or the hospital's negligence then you may be able to claim compensation. After discussing with your research doctor, please make the claim in writing to Dr William Mandy who is the Chief Investigator for the research and is based at University College London. The Chief Investigator will then pass the claim to the Sponsor's Insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

Who has reviewed the study?

All proposals for research using human subjects are reviewed by an Ethics Committee before they can proceed. This proposal was reviewed by University College London Research Ethics Committee.

Who is organising and funding the study?

Researchers at University College London are organising this study. They will not get any extra money for doing this research.

The research is being paid for by University College London, who are sponsoring this study.

What will happen to the results of the study?

When the study has finished we will present our findings to other researchers and doctors, and we will put the results in academic magazines. The results will be written up as part of Laura Hull's PhD thesis. The results might also be discussed at conferences, although we will only refer to groups so no individual responses will be discussed. All results will be anonymous, which means that you will not be able to be identified from them. If you are interested in finding out more about the results of the study, tell the researcher and we can send you a summary when we have finished analysis.

What next?

Please read through this information sheet with your parent/caregiver. If you have any further questions about the study, we are happy to discuss these with you: email Laura at laura.hull.14@ucl.ac.uk.

Once you and your parent/caregiver are happy to take part in the study and have had all your questions answered, we will contact your parent/caregiver to arrange a time and location for you to come and complete the study. Agreeing to take part does not mean you have to do so; you can still stop at any time and do not have to give a reason for stopping.

What to remember:

- The study will take place in a private room. Only the researcher and your parent/caregiver (if you want them there) will be able to hear or see your responses while you give them.
- The study will take around two hours, and you can take as many breaks as you need if you get overwhelmed or for any other reason.
- You don't have to participate if you want to. Nothing bad will happen to you if you change your mind.

- When the study is completed you can receive a summary of all the findings. No one will be able to know that you took part or what your responses were from this summary.
- Your privacy will be respected. Only the researchers and your clinicians will ever have access to your responses.
- We are very grateful to you for helping us to learn more about autistic teenagers' social skills, so that we can help other people to understand as well.

Appendix E – Joint Theses Contribution

The current thesis was completed as part of a joint research project with fellow Trainee Clinical Psychologist, Louise Chapman, and Laura Hull. Some of the data collected during this research project formed part of Laura Hull's PhD.

In terms of contributions, Laura applied for ethics and had started recruitment prior to me and Louise joining the project. Due to the research already being underway, myself and Louise assisted with data collection. As such, Louise, Laura and I each completed the research battery with roughly equal amounts of participants.

The focus of each of our projects was distinct. Whilst mine focused upon the role of VIQ in social camouflaging, Laura's PhD investigated the psychometric properties of the CAT-Q, and how this relates to other measures of camouflaging. Contrastingly, Louise's research was purely qualitative in nature. After completing the pre-agreed battery of tests, Louise invited participants to be interviewed about their experiences of social camouflaging and mental health. As such, each project was distinct.

Appendix F – Assent and Consent Forms

Study Number: 17/0554
Patient Identification Number for this trial:

CONSENT FORM: ASD PARENT/CAREGIVER

Title of Project: Social Skills in Autistic Teenagers

Name of Researcher: Laura Hull

Please initial box

1. I confirm that I have read and understand the information sheet dated 19/12/2017 (version 5/6) for the above study. I have had the opportunity to consider the information, discuss it with my child, ask questions and have had these answered satisfactorily.

2. I understand that my and my child’s participation is voluntary and that we are free to withdraw at any time without giving any reason, without my child’s medical care or legal rights being affected.

3. I understand that relevant sections of my child’s medical notes and data collected during the study, may be looked at by individuals from the sponsor of the trial (University College London) and responsible persons authorised by the sponsor, from regulatory authorities or from the NHS Trust, where it is relevant to my child’s taking part in this research. I give permission for these individuals to have access to my child’s records.

4. I agree for myself and my child to take part in the above study.

5. I consent for audio and video recordings of my child’s assessments to be made.

6. I consent for researchers to access recordings of my child’s responses.

7. I agree for my and my child’s anonymised data to be used in future research studies. (Optional)

8. I agree for the researchers to store my and my child’s personal data so they can contact us in the future to ask if we would like to take part in other studies (Optional)

Name of Patient

Name of Parent Date Signature

Name of Person Date Signature

taking consent

Name of Chief Investigator
(if different to the person taking consent)

Date

Signature

When completed: 1 for participant; 1 (original) for researcher site file; 1 to be kept in medical notes.

Study Number: 17/0554
Patient Identification Number for this study:

ASSENT FORM: ASD ADOLESCENT 13-15

Title of Project: Social Skills in Autistic Teenagers

Name of Researcher: Laura Hull

Please complete this form after you have read the Information Sheet and discussed it with your parent/caregiver. If you are unsure about any of the statements, or if you have any further questions about the study, please ask the researcher (Laura) or discuss this with your parent/caregiver before continuing.

Please initial box

1. I confirm that I have read and understand the information sheet dated 19/12/2017 (version 4) 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 medical care or legal rights being affected.

3. I agree for audio and video recordings of my responses to be made.

4. I agree for researchers to watch and listen to recordings of my responses.

5. I understand that my responses will be stored securely and any personally identifiable information will be deleted once data have been coded.

6. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from the sponsor of the trial (University College London) and responsible persons authorised by the sponsor, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

7. I agree for my anonymised data to be used in future research studies. (Optional)

8. I agree for the researchers to store my personal data so they can contact me in the future to ask if I would like to take part in other studies (Optional)

9. I agree to take part in this study.



Name of Patient

Date

Signature

Name of Person
taking assent

Date

Signature

Name of Chief Investigator
(if different to the person taking assent)

Date

Signature

When completed: 1 for participant; 1 (original) for researcher site file

Study Number: 17/0554
Patient Identification Number for this study:

CONSENT FORM: ASD ADOLESCENT, 16-19

Title of Project: Social Skills in Autistic Teenagers

Name of Researcher: Laura Hull

Please complete this form after you have read the Information Sheet and discussed it with your parent/caregiver. If you are unsure about any of the statements, or if you have any further questions about the study, please ask the researcher (Laura) or discuss this with your parent/caregiver before continuing.

Please initial box

1. I confirm that I have read and understand the information sheet dated 19/12/2017 (version 6) 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 medical care or legal rights being affected.

3. I consent for audio and video recordings of my responses to be made.

4. I consent for researchers to watch and listen to recordings of my responses.

5. I understand that my responses will be stored securely and any personally identifiable information will be deleted once data have been coded.

6. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from the sponsor of the trial (University College London) and responsible persons authorised by the sponsor, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

7. I agree for my anonymised data to be used in future research studies. (Optional)

8. I agree for the researchers to store my personal data so they can contact me in the future to ask if I would like to take part in other studies (Optional)

9. I agree to take part in this study.

_____ _____ _____
Name of Patient Date Signature

_____ _____ _____
Name of Person Date Signature
taking consent

_____ _____ _____
Name of Chief Investigator Date Signature
(if different to the person taking consent)

When completed: 1 for participant; 1 (original) for researcher site file