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CATHERINE E. SADDINGTON BSc (Hons)

OBSESSIONS AND COMPULSIONS IN AUTISTIC SPECTRUM  
DISORDERS

**Section A: The occurrence of comorbid obsessive compulsive disorder in individuals with autistic spectrum disorders: Prevalence and presentation**

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A thesis submitted in partial fulfilment of the requirements of Canterbury Christ Church University for the degree of Doctor of Clinical Psychology

JULY 2013

SALOMONS

CANTERBURY CHRIST CHURCH UNIVERSITY

**CANTERBURY CHRIST CHURCH UNIVERSITY**  
**Doctorate in Clinical Psychology (D.Clin.Psychol.)**

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## **Acknowledgements**

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## Summary of portfolio

**Section A:** reviews existing literature regarding the possible occurrence of comorbid obsessive-compulsive disorder (OCD) in individuals with autistic spectrum disorders (ASD). Current estimates of comorbidity rates and the factors possibly contributing to their variability are discussed before reviewing literature examining literature exploring the similarities and differences in the experiences of individuals with ASD and OCD, including symptom profiles. This literature is considered in terms of OCD diagnostic criteria and theoretical models.

**Section B:** is an empirical, cross-sectional study aiming to explore and compare the obsessive-compulsive phenomenon experienced by adults with diagnoses of ASD or OCD and a healthy, non-clinical control group. Symptom profiles and associated emotions and responses are considered, both in terms of between-group comparisons and in relation to current understandings of OCD. Relationships between the presence of autistic traits and OCD severity are also discussed.

**Section C:** is a critical appraisal of the research process which reflects on learning taken from the experience and skills developed and also considers implications for clinical practice and further research.

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Catherine Saddington BSc Hons.

**Major Research Project**

**SECTION A**

**The occurrence of comorbid obsessive  
compulsive disorder in individuals with autistic  
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A thesis submitted in partial fulfilment of the requirements of  
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July 2013

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## Abstract

Recent research has found comorbid anxiety disorders to be common amongst individuals with Autistic Spectrum Disorders (ASD) and subsequently there has been increasing focus on the assessment and treatment of such disorders in this population. The diagnosis and treatment of Obsessive Compulsive Disorder (OCD) has however been relatively neglected in this group by comparison. This may be partly due to diagnostic-overshadowing, with symptoms of OCD closely resembling the restricted and repetitive behaviour common in ASD. Furthermore, some suggest that in contrast to OCD, the obsessive and compulsive behaviours displayed by individuals with ASD are not a source of distress and thus are not indicative of comorbid OCD.

Estimated rates of comorbid OCD in ASD are reviewed. While estimates vary greatly, possibly due to the heterogeneous nature of this population and the variation in measures and criteria used, the majority suggest the occurrence of OCD in individuals with ASD is higher than in the general population. The presentation of OCD symptoms and associated emotions is also reviewed. Some studies have suggested that patterns of symptoms may vary between individuals with OCD and ASD, but results are inconsistent. Perhaps more importantly, while limited, the available empirical literature suggests that, in contrast to previous speculation, obsessions and compulsions can be distressing and ego-dystonic experiences in individuals with ASD. Further research needs to be dedicated to this area to ensure that comorbid OCD is not overlooked due to diagnostic overshadowing and to ensure adequate assessment and access to intervention where required.

## **Introduction**

### **Autistic Spectrum Disorders**

The term Autistic Spectrum Disorders (ASD) is used to refer to a set of neurodevelopmental disorders, encompassing Autism, High-functioning Autism (HFA), Atypical Autism, Asperger's Syndrome (AS) and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). ASD are characterised by a triad of impairments; impaired social communication, interaction and imagination (expressed as restricted interests and repetitive behaviours; APA, 2000). While previous estimates suggested ASD prevalence was approximately 60/100,000 (Fombonne, 2003), Baron-Cohen et al. (2009) recently suggested it was over double this, at 157/100,000. It is estimated that 29.4% of individuals with ASD have mild-moderate learning disabilities (LD) and 41.9% have severe-profound LD (Fombonne, 1999).

### **Anxiety Disorders and ASD**

In addition to the triad of impairments, individuals with ASD frequently experience comorbid anxiety disorders (Simonoff et al., 2008). Despite suggestions that symptoms of anxiety disorders are three times more prevalent in adults with ASD compared to other developmental disabilities (Gillott and Standen, 2007, as cited in Davis, Saeed & Antonacci, 2008), Rumsey, Rapoport and Sceery (1985) argue that diagnosis of comorbid disorders in this population remains less common. This may be partly due to the lack of consensus/guidelines regarding separating difficulties related to ASD and those indicative of other disorders, particularly OCD, where the obsessions and compulsions characterising this disorder may be hard to distinguish from the restricted and repetitive behaviours (RRBs) characteristic of ASD (Matson & Dempsey, 2009).



While obsessional thoughts occur commonly across the general population (Rachman & De Silva, 1978; Salkovskis & Harrison, 1984), Russell, Mataix-Cols, Anson and Murphy (2005) propose the cognitive style and anxiety common in ASD may influence how such experiences are appraised, leading to the development of comorbid OCD. However, diagnostic overshadowing may result in under-diagnosis of OCD in this population and a subsequent lack of access to interventions (Bejerot, Nylander & Lindstrom, 2001).

### **Repetitive Behaviour and Restricted Interests in ASD**

Numerous theories have been proposed to explain the presence of the RRBs necessary for ASD diagnosis, including viewing them as homeostatic mechanisms to modulate arousal, or the result of impaired metallizing ability, weak central coherence or executive dysfunction (see Turner, 1999, for review). Turner (1999) suggests no theory is likely to account for all RRBs and a single RRB may have multiple causes. While some suggest the deficits associated with ASD may lessen somewhat with age (Shattuck et al, 2007), improvements in RRBs may be limited in comparison to improvements in social interaction and communication (Fecteau, Mottron, Berthiaume & Burack, 2003; Piven, Harper, Palmer & Arndt, 1996; Seltzer, Shattuck, Abbeduto & Greenberg, 2003).

While RRBs occur across all individuals with ASD, Militerni, Bravaccio, Falco, Fico and Palermo (2002) highlight the lack of homogeneity in presentations. RRBs can include behavioural (e.g. stereotypies), communicative (e.g. echolalia) and cognitive (e.g. insistence on sameness) components (Chowdhury, Benson & Hillier, 2010) and are subdivided into four subtypes within DSM-IV (APA, 2000); preoccupations with restricted and stereotyped patterns of interest, inflexible

adherence to non-functional routines/rituals, repetitive motor mannerisms and preoccupation with parts of objects (see Fischer-Terworth & Probst, 2009; Leekam, Prior & Uljarevic, 2011, for reviews).

While RRBs present in various forms, factor analyses suggest they can be classified as either 'high-order' (including rituals and restricted interests) or 'low-order' (including stereotyped movements and self-injurious behaviour; Cuccaro et al., 2003; Szatmari et al., 2006). Higher-order RRBs have been found to be more common in older individuals (Georgiades, Papageorgious and Anagnostou, 2010) and to be associated with higher-IQ (Militeni et al, 2002). No significant associations between RRB types and gender have been found (Lai et al, 2011).

### **RRBs or 'Obsessions' and 'Compulsions': Rationale for Review**

It is argued that higher-order RRBs often resemble the obsessive-compulsive phenomena characteristic of OCD, leading to suggestions that their presence may sometimes indicate the presence of OCD and warrant diagnosis (Leekam et al., 2011). This is however the subject of debate with some arguing these terms should be used with caution when describing such behaviours in individuals with ASD, that the behaviours are conceptually and phenomenologically different in the two (Baron-Cohen, 1989) and that a secondary diagnosis of OCD may only increase confusion (Zandt, Prior & Kyrios, 2007). Alternatively, diagnostic-overshadowing and lack of consensus regarding secondary OCD diagnoses may result in behaviours being misattributed to ASD, OCD diagnoses being overlooked and appropriate interventions not being provided.

Numerous studies have also proposed a shared neurological basis underlying ASD and OCD. Discussion of this work is beyond the scope of this review (see

Gross-Isseroff, Hermesh & Weizman, 2001, and Stein, 2000, for reviews). Gross-Isseroff et al. (2001) argue that it remains uncertain whether OCD is a central component of ASD, and thus not a comorbid disorder, or whether it is a separate disorder which can be present in addition to ASD. The latter, they suggest, may indicate that the reported neuro-biological overlap between the two may be artefactual.

While the potential shared neurological basis of OCD and ASD has been reviewed, no review has been completed regarding the presentation of OCD in individuals with ASD. As discussed, such a review may be of clinical importance, particularly in light of suggestions that comorbid OCD may be overlooked and interventions not accessed in individuals with ASD. The current review will therefore examine existing literature regarding estimated rates of comorbid OCD in individuals with ASD, before going on to explore literature examining similarities and differences in the presentation of obsessive-compulsive phenomena in these two groups, both in terms of the symptoms presented and how they are experienced. Consideration will be given to how reported presentations link to current conceptualisations of OCD.

A systematic literature search (Appendix A) identified 21 studies (including one previous meta-analysis) exploring comorbid OCD in ASD along with seven studies directly comparing obsessive-compulsive phenomena in OCD and ASD. These studies form the basis of the following review.

## **Review of the Literature**

### **Rates of Comorbid OCD in ASD**

While OCD prevalence is estimated at 2-3% (Hollander, 2005; Zohar, 1999), reported rates in individuals with ASD vary from 0% (Bradley, Ames & Bolton, 2011) to 72.2% (Lai et al, 2011). A meta-analysis examining the occurrence of anxiety disorders in children with ASD suggested 17.4% had comorbid OCD (van Steensel, Bogels & Perrin, 2011). However, the authors noted the wide heterogeneity in reported rates. Reported prevalence rates in adults have also varied (Bakken et al., 2010; Hutton, Goode, Murphy, Couteur & Rutter, 2008).

There are a number of factors which may contribute to the variation in rates of comorbid OCD in ASD reported in the studies summarised in Appendix B.

#### **Measures and respondent.**

In addition to difficulty distinguishing OCD symptoms from RRBs, it is argued that symptom identification is further impaired by the lack of measures validated for use with this population (Leyfer et al., 2006). Of the twenty studies summarised in Appendix B, only four used measures designed specifically for individuals with ASD. Rates of diagnosis obtained through use of existing standardised diagnostic measures and measures specifically designed for use with ASD have yet to be compared in a single study.

Leyfer et al., (2006) developed the Autism Comorbidity Interview (ACI). This measure aimed to take account of children's behaviour at a baseline and consider the emergence of any symptoms in relation to this. Inter-rater and test-retest reliability were found to be good for OCD. Leyfer et al.'s estimated prevalence was

however significantly higher than that found by Mazefsky, Kao and Oswald (2011) using the same measure. The authors suggested this may have been due to parents' inferences regarding their child's subjective mental experiences being taken as evidence of obsessions, stating that without such inferences, only a small minority of children would meet diagnostic criteria.

Using the Psychopathology in Autism Checklist (PAC (Helverschou, Bakken, & Martinsen, 2009)) Bakken et al. (2010) found that OCD had the lowest prevalence rate in children with LD or ASD compared to other anxiety disorders and that the difference in prevalence rates between groups was lowest for OCD. This suggested that, using the PAC, the RRBs present in the ASD group were not being taken as indicators of OCD, thereby avoiding artificially inflating estimated OCD prevalence in this group.

The majority of studies utilised parents'/carers' reports, thus relying on them to infer their child's subjective mental state. However, Muris, Steerneman, Merckelbach, Holdrinet & Meesters (1998) suggested parents tend to underestimate children's experiences of anxiety. Conversely, Mazefsky et al. (2011) cautioned against the use of self-report measures to determine diagnoses in this population. When comparing the reports of adolescents with HFA/AS to results of parental interviews, self-reports were found to yield high rates of false positives. In addition, all self-report scores were above the cut-off for OCD, regardless of whether or not diagnostic interviews indicated the presence of the disorder, suggesting self-report may lead to an over-estimation of prevalence rates.

**Recruitment.**

Rates of comorbid OCD may sometimes be over-estimated due to recruitment methods. Half the studies summarised in Appendix B recruited participants through specialist clinics, where individuals with more complex presentations are perhaps over-represented. Mattila et al. (2010) found rates of comorbid OCD to be over twice as high in individuals with ASD recruited from specialist clinics compared to a community sample. Recruitment through support groups/voluntary organisations may also have attracted participants more interested in the research area due to the presence of comorbid difficulties. Using a stratified population-based sample and a follow-up of children previously diagnosed with ASD, prevalence rates of 8.2% and 3.7% were found in children and adults by Simonoff et al. (2008) and Hutton et al. (2008), respectively.

**Diagnostic subtype.**

As previously discussed, individuals with ASD do not represent a homogeneous population, with diagnostic subtype and level of LD perhaps being particularly relevant variables due to suggestions that higher-order behaviours are more common amongst higher-functioning individuals. Furthermore, studies including individuals with moderate-severe LD and impaired communication may rely heavily on inferences drawn by parents/carers. The majority of studies have included a range of diagnostic subtypes and cognitive functioning. Six studies looked at single diagnostic subtypes and only one compared prevalence rates across two sub-types (HFA and AS; Mulkaddes, Herguber and Tanidir, 2010b). Further direct comparisons of sub-types and exploration of association with level of LD are required.

### **Age.**

The majority of studies have examined the presence of comorbid OCD in child and adolescent populations. However, OCD has been found to have a bimodal onset, occurring at around ten years or the early 20s (Geller, 2003, as cited in Reaven and Hepburn, 2003). Hutton et al. (2008) found that 3.7% of a sample of individuals with ASD who did not have OCD during childhood/adolescence, met diagnostic criteria in adulthood. Children with OCD and ASD have also been found to be significantly older than those without OCD (Gjevik, Eldevik, Fjaeran-Granum, & Sponheim, 2011), suggesting the age range of a sample may influence reported prevalence rates.

### **Gender.**

To date, only two studies have compared the occurrence of OCD in males and females with ASD. Lai et al. (2011) and Simonoff et al. (2008) reported no gender differences in their samples, however this factor requires further exploration with different age-groups, diagnostic subtypes and using measures validated for use with this population.

### **Comparisons of Obsessive and Compulsive Symptoms in ASD and OCD**

While estimated rates of comorbid OCD in ASD have varied widely, another means of exploring the presence in ASD is through direct comparison to individuals with OCD, both in terms of obsessive-compulsive symptom patterns and also severity. Baron-Cohen (1989) argued that while checking and hand-washing are common compulsions in individuals with OCD, such presentations are rare in

individuals with ASD. He therefore suggested the behaviours exhibited in these two disorders differ significantly.

Existing literature comparing obsessive-compulsive symptoms in OCD and ASD will be summarised and discussed below. Four studies directly compared patterns of obsessions and compulsions in ASD and OCD; two with child and adolescent populations (Ruta, Mugno, D'Arrigo, Vitiello & Mazzone, 2010; Zandt et al., 2007) and two with adult populations (McDougle et al., 1995; Russell, Mataix-Cols, Anson & Murphy, 2005). See Appendices C and D for summaries of methodologies and findings.

Zandt et al. (2007) found significantly more obsessions and compulsions in children with OCD compared to ASD and reported this difference occurred across all obsession and compulsion categories with the exception of compulsions involving others, ordering compulsions and religious obsessions, in which the groups were comparable. In contrast, Ruta et al. (2010) found children with AS tended to have higher frequencies of saving/hoarding obsessions and ordering and hoarding compulsions compared to children with OCD, although these differences were non-significant. While the OCD group had significantly higher frequencies of aggressive and contamination obsessions and checking compulsions than the AS group, rates of saving/hoarding obsessions and repeating, cleaning, ordering and hoarding compulsions were significantly more frequent in the AS group compared to typically developing controls. In contrast to Zandt et al., the ASD group in Ruta et al.'s study all had the same diagnostic subtype (AS), which was confirmed using standardised assessments. Although diagnoses in Zandt et al.'s ASD group were not confirmed using standardised tools and the diagnostic subtypes included varied, the authors



argued this did not impact on findings as removal of participants with Autism and PDD-NOS from analyses did not alter results.

Studies comparing obsessions and compulsions in adults used discriminant function analysis to determine whether ASD and OCD groups could be distinguished by symptom patterns. While, like other studies discussed, McDougle et al.(1995) used the Yale-Brown Obsessive-Compulsive Scale (Y-BOCS; Goodman et al., 1989a,b) to assess the presence of obsessions and compulsions, the authors changed the widely used categories to form new categories (some consisting of single items) which they suggested were more characteristic of ASD. Results revealed the ASD group experienced more compulsions than obsessions. The OCD group was also found to have significantly more obsessions than the ASD group. Seven types of obsessions and compulsions which best predicted group membership were identified, leading the authors to conclude that symptoms profiles differed significantly between groups. However, these results must be interpreted with caution due to the significant differences in IQ between groups, with 56% of the ASD group having a learning disability and 30% being non-verbal. As well as possibly impacting on the types of compulsions displayed, this may have led to an underestimation of the presence of obsessions in the ASD group as observation may have been relied on to assess symptom presence. Lewis and Bodfish (1998) proposed the differences found by McDougle et al. (1995) mirrored those observed between adults and children with OCD, thus suggesting the finding may have been due to differences in developmental age/IQ and not diagnosis.

When comparing IQ-matched adults with OCD and AS/HFA, Russell et al (2005) found comparable frequencies of obsessions and compulsions. The two diagnostic groups were best distinguished by a single obsession and compulsion (somatic obsessions and repeating compulsions), which were both more common in the OCD group. However, 25% of the AS/HFA group were also found to have comorbid OCD and analysis was repeated to compare the pure OCD group to those with comorbid OCD and ASD (n=10). Again these two groups were best distinguished by a single obsession and compulsion. Somatic obsessions were found to be significantly more frequent in the OCD group whereas sexual obsessions were significantly more frequent in the comorbid group.

Russell et al.'s finding combined with previous research exploring rates of comorbid OCD in ASD raises the question of whether the studies discussed have been comparing two distinct groups, or whether their samples may encompass a third group of individuals with both ASD and OCD. A further three studies have explored the similarities and differences in presentations of those with a primary OCD diagnosis and those with ASD who also fulfil diagnostic criteria for OCD (see Appendices C and D for summaries). Two have compared child and adolescent populations (Lewin & Wood, 2011; Mack et al., 2010) and only one has compared adult populations (Cath, Ran, Smit & Comijs, 2008). While the diagnosis of OCD in this population is itself subject to debate, such studies provide evidence as to whether the apparent obsessive-compulsive presentations in this group appear similar to those in individuals with a primary OCD diagnosis.

Lewin et al., (2011) found differences in patterns of obsessions and compulsions, with children with 'pure OCD' experiencing significantly higher levels of sexual obsessions and cleaning, checking and repeating compulsions compared to

children with ASD and apparent comorbid OCD. The authors suggested these particular compulsions were more likely to be responses to anxiety-provoking obsessions which they proposed were lower in individuals with ASD, for whom compulsions may be a source of pleasure.

In contrast, Mack et al. (2010) and Cath et al. (2008) found no significant differences in patterns of obsessions and compulsions between the two groups in child or adult populations. However, these studies utilised extremely small samples and may therefore have lacked power to detect any existing differences. Furthermore, the comorbid ASD plus OCD group in Cath et al.'s study were not identified using a validated diagnostic tool and only half scored above cut-off on an ASD screening measure (Autism Quotient; Baron-Cohen, Wheelwright, Skinner, Martin, & Clubey, 2001).

While Cath et al.'s study was strengthened by the inclusion of a typically developing control group, none of the studies comparing the symptoms of individuals with comorbid OCD and ASD to those of individuals with 'pure OCD' included a 'pure ASD' group to examine whether the symptoms reported were similar in all individuals with ASD or whether there is a subgroup with comorbid OCD.

### **True OCD?**

“Even if the clinical phenomenology of OCD symptoms may be similar in the two groups, individuals with ASD tend not to show distress associated with their fixed beliefs and do not perform rituals to alleviate anxiety.” (Ruta et al., 2010, p18)

While the studies discussed above explored whether obsessive-compulsive symptoms displayed by individuals with OCD and ASD are similar, less attention has been given to how these experiences are distinguished from the RRBs common to ASD. Many argue the key distinction between lies in the functions of these behaviours and the associated emotions.

DSM-IV criteria for OCD (APA, 2000; Appendix E) describe the presence of obsessions and/or compulsions which occupy over an hour a day or cause marked distress or significant impairment. The individual must also recognise the excessive or unreasonable nature of their symptoms, although this criterion does not apply to children and a 'with poor insight' descriptor is available for adults. Similarly, ICD-10 criteria (WHO, 1992; Appendix F) describe obsessions and compulsions as distressing and not enjoyable or pleasurable experiences. While appearing phenotypically similar, no such distress is reported to be common in the RRBs associated with ASD and in contrast these experiences are suggested to be ego-systonic and a not a source of distress, compared to the distressing and ego-dystonic symptoms of OCD. The ego-dystonic quality is described as resulting in obsessions which "are not experienced as voluntarily produced, but rather as thoughts that invade consciousness and are experienced as senseless or repugnant" (Jakes, 1996, p5). This distinction has led to suggestions that the experiences of those with ASD cannot be conceptualised as true OCD (e.g. Baron-Cohen, 1989; Ivarsson & Merlin, 2008; Ruta et al., 2010). This debate is likely to be a significant contributing factor to the variations in estimated prevalence rates. The 0% prevalence rate of comorbid OCD in ASD reported by Bradley et al. (2011) was attributed by the authors to an inability to ascertain the presence of ego-dystonia.

The apparent presence of obsessive-compulsive symptoms across various other disorders including ASD, tic disorders, body dysmorphic disorder, eating disorders and trichotillomania, has resulted in suggestions that these symptom overlaps may be best conceptualised as representing a spectrum of obsessive-compulsive behaviour rather than the presence of comorbid OCD. According to the proposed obsessive-compulsive spectrum model, disorders would be considered in terms of their location on a compulsivity-impulsivity dimension, with those including behaviours aimed at reducing anxiety/minimizing harm falling at the compulsive pole and those characterised by pleasure seeking behaviours falling at the impulsive end (Bartz & Hollander, 2006; Hollander & Zohar, 2004, as cited in Abramowitz et al, 2009). While some have argued the spectrum model is supported by family and neuroimaging studies, this is an area where there has been considerable debate (see Abramowitz et al., 2009 for review). The suggested model does however raise questions in relation to the diagnosis of OCD in individuals with ASD and regarding where ASD may fall on such a spectrum.

While the ego-systonic nature of obsessions and compulsions in ASD and the contrasts to OCD is an area which has been the subject of much speculation, little empirical research has been conducted which supports these assumptions.

### **Evidence of distress and ego-dystonia associated with obsessions and compulsions in ASD.**

In addition to comparing symptoms, five studies summarised in Appendices C and D utilised the Y-BOCS severity scale; consisting of items relating to time occupied by obsessions and compulsions, interference and distress caused, resistance exercised and level of control.

Ruta et al (2010) found that severity was significantly higher in children with OCD compared to ASD. However, those with ASD still fell into the 'mild impairment' category and scored significantly higher than typically developing controls. Russell et al., (2005) also found severity to be higher in adults with OCD compared to ASD. However, the authors unfortunately did not separate the comorbid OCD and ASD group when examining levels of severity. Eight of the verbal participants with ASD in McDougle et al.'s (1995) study reported actively trying to suppress obsessive thoughts or resist compulsive behaviour, suggesting these experiences were unwanted and a source of distress/interference.

When comparing children with apparent comorbid ASD and OCD to those with pure OCD, no differences were found in total severity, obsession severity or compulsion severity (Lewin et al., 2011; Mack et al; 2010), suggesting these groups were equally distressed and experienced equal levels of interference. In contrast, Cath et al (2008) reported higher severity in their adult pure OCD group compared to their comorbid OCD plus ASD group. This difference was however due to differences in obsession severity with levels of compulsion severity being comparable.

The conclusions which can be drawn from severity scores regarding levels of distress are however limited due to the variety of items contributing to these scores. In addition to items directly assessing distress, items regarding time occupied and level of interference also contribute. These factors do not necessarily imply experiences are distressing/unwanted as pleasurable experiences may also be time-consuming and interfere with activities. Therefore, these individual factors need to each be compared in individuals with OCD and ASD.

Another way of inferring distress is through help-seeking. Increased levels of autistic traits have been reported in individuals diagnosed with OCD (e.g. Anholt et al., 2010; La Salle et al., 2001). Bejerot et al. (2001) found elevated rates of ASD traits in 20% of their sample of adults with OCD, with 4.7% later receiving diagnoses of AS. The authors argued the fact these individuals were seeking treatment for OCD suggests that obsessive-compulsive symptoms in individuals with ASD are not always ego-systonic and can be distressing.

The types of obsessions reported by individuals with ASD in the papers summarised in Appendix C may also be incompatible with the conceptualisation of such obsessions as examples of pleasurable restricted interests. Anagnostou et al. (2011) argued their finding that contamination was the most common obsession reported by children/adolescents with ASD was incompatible with this conceptualisation.

Much of the distress associated with obsessions and compulsions stems from the ego-dystonic nature of these experiences. While studies requiring experiences to be ego-dystonic in order to be classified as obsessions and compulsions have reported OCD rates of 25-37% in ASD samples (Green, Gilchrist, Burton & Cox, 2000; Leyfer et al., 2006, respectively), such studies utilised parental reports and thus the ego-dystonic nature of experiences was assessed by relying on parents to accurately infer their child's subjective experiences.

Only one study to date has attempted to directly assess the ego-dystonic quality of obsessive-compulsive symptoms in individuals with ASD. While no validated measure of this concept exists, Cath et al. (2008) designed four questions to assess the extent to which obsessions and compulsions were experienced as

excessive/unreasonable, strange/abnormal and inappropriate and the extent to which the individual felt they needed to control them. No differences were found between adults with OCD and those with apparent comorbid ASD and OCD. While this sample were high-functioning and perhaps more able to verbalise their experiences, McDougle et al. (1995) argued that an inability to express such feelings must not be taken to indicate their absence. The small sample size of this study may also mean that power was not sufficient to detect any actual differences in ego-dystonia and so further investigation is required.

### **Cognitive-behavioural model of OCD.**

In addition to exploring whether the obsessive-compulsive experiences of individuals with ASD fulfil OCD diagnostic criteria, another area of interest is whether these experiences fit with current models of OCD. The cognitive-behavioural model of OCD describes compulsions as occurring in response to anxiety-provoking obsessive thoughts (Jakes, 1996; Salkovskis, 1989). This anxiety is suggested not to be due to obsession content specifically, but rather how they are appraised e.g. as indicating the individual may be capable of/responsible for harm. This model proposes that compulsive behaviours are reinforced by the temporary reduction in anxiety they provide. Compulsions also contribute to symptom maintenance by preventing the testing of the appraisals of obsessions. By only classifying acts which were reported to be preceded by feelings of discomfort/anxiety as well as being unwanted and distressing as compulsions, Mack et al (2010) found the number of compulsions to be comparable in children with pure OCD and those with ASD and comorbid OCD.



While diagnostic criteria stipulate either obsessions or compulsions must be present to receive an OCD diagnosis, Foa et al. (1995; as cited in Abramowitz, 2009) reported that 96% of individuals with OCD experience both phenomena, thus appearing consistent with the previously mentioned model's proposed relationship between the two. In contrast, McDougle et al. (1995) reported their ASD group had more compulsions than obsessions, with only 64% reporting both phenomena compared to 90% of the OCD group. The lower rates of obsessions reported by McDougle et al. is perhaps not surprising given the level of functioning and communication difficulties present in their sample. Research suggests that while obsessions and compulsions typically co-occur in adults, compulsions without obsessions are more commonly reported in children (Gekler et al., 1998, as cited in Rooney, Alfano, Walsh & Parr, 2011; Swedo et al, 1989). Swedo et al. hypothesise this may be due to lack of cognitive ability to report on these phenomena. Recent work has suggested that such difficulties in reporting may not be limited to children or individuals with lower cognitive ability. Leonard and Riemann (2012) found that adults with OCD also did not all initially report both obsessions and compulsions. Subsequent administrations of OCD measures and clinical interviews however revealed that all participants experienced both phenomena. The authors therefore suggested that, in line with cognitive-behavioural models of OCD, diagnostic criteria should stipulate the presence of both obsessions and compulsions, hypothesising that reporting of one phenomena but not the other is due to individuals' lack of understanding of their symptoms and is exacerbated by using self-report measures.

While no studies have compared appraisals of obsessions in individuals with OCD and ASD, the limited evidence suggests that individuals with ASD may often experience both obsessions and compulsions and that difficulties reporting these

experiences are not limited to this population and do not necessarily imply their absence. Furthermore, one study has reported that, consistent with current cognitive-behavioural models, the compulsions experienced by children with ASD are often preceded by feelings of anxiety. This is an area which requires further exploration, including adult populations. As well as furthering our understanding of how the obsessions and compulsions experienced by individuals with ASD compare to those experienced by individuals with OCD, including whether they fit with accepted models of the disorder, such work may also have implications for interventions. Guidelines recommend the use of CBT including exposure and response prevention (ERP) as a psychological intervention for OCD (National Institute for Clinical Excellence, 2005). Such interventions are based upon the previously outlined conceptualisation of compulsions as responses to the anxiety associated with the appraisal of obsessions and as such it would be of importance to ascertain whether the experiences of individuals with ASD were compatible with this conceptualisation before commencing intervention.

### **Discussion**

Estimated rates of comorbid OCD in individuals with ASD vary widely, however, the majority have suggested rates equal to or greater than those found across the general population. The variation reported may be partly due to the heterogeneous nature of this population, with factors such as diagnostic subtype, age and IQ possibly having an impact. Further research is required to explore such associations and also to focus on the development of measures suitable for this population, particularly for those who may have an associated LD. The samples studied are typically drawn from specialist clinics where the level of complexity may be higher and where comorbidities have been assessed for the purposes of

research. It would therefore be of interest to examine and compare rates of comorbid OCD as diagnosed in routine clinical practice and community samples.

The lack of guidelines regarding diagnosing comorbid OCD in those with an existing diagnosis of ASD may also be responsible for the variation in reported prevalence rates, along with views that such behaviours are typical of individuals with ASD, are not distressing and thus do not warrant further assessment or diagnosis. The possibility of diagnostic-overshadowing is of particular concern given the findings of the existing literature comparing obsessions and compulsions in OCD and ASD.

While some variations in the pattern of obsessions and compulsion reported in ASD and OCD populations have been reported, suggesting that the two groups can be distinguished on this basis, the differences reported are not consistent across studies and may in some cases be influenced by additional factors such as IQ (McDougle et al., 1995).

One area which had been the subject of little research, but significant speculation, and which appears key to the consideration of an OCD diagnosis, is the distress and ego-dystonia associated with experiences of obsessions and compulsions. While extremely limited, existing literature suggests that these experiences may cause some distress in individuals with ASD, although perhaps less than that experienced by individuals with OCD. This is an area which warrants further research, particularly regarding how the occurrence of obsessive thoughts are appraised in this population and whether compulsions attempt to alleviate associated distress. Further thought is also required regarding how such

experiences can be captured, particularly in those who have significant communication impairments and thus may be less able to verbalise them.

Cath et al (2008) suggest the sometimes subtle nature of social and communication impairments mean that individuals with ASD do not present to services until adulthood, when a period of stress is encountered. The authors suggest that at these times, anxiety disorders are often considered over ASD. Bejereot et al., (2001) also suggested that the presence of ego-dystonic OCD can sometimes mask the presence of HFA or AS. It would therefore be of interest to explore the factors which lead clinicians to consider assessment of either ASD or OCD in individuals presenting with apparent obsessions and compulsions. If, as suggested, this decision is often based on the reported ego-dystonic nature of experiences, this may be problematic in individuals who are less able to communicate these experience or those who lack insight.

Research suggesting the obsessions and compulsions experienced by individuals with ASD can be a sources of distress/interference highlights the need for appropriate assessment and subsequent access to interventions in this population. While individual case-studies of children with comorbid ASD and OCD have suggested that CBT including ERP may be an effective intervention for this population (Reaven & Hepburn, 2003; Lehmkuhl, Storch, Bodfish, & Geffken, 2008), a larger study of adults suggested that while overall the intervention group showed significantly greater improvements compared to treatment as usual controls, not all subjects responded to this intervention. The use of CBT to address other anxiety disorders in this population has been the subject of larger scale research and has shown promising results, with some modifications recommended (Attwood, 2004; Reaven, 2009). Larger-scale research is required to explore the effectiveness of

OCD interventions in individuals with ASD, highlight any modifications required and also to explore the characteristics of individuals who may not respond to such interventions.

### **Conclusion**

While extremely limited, the existing evidence suggests the apparent obsessive-compulsive symptoms in individuals with ASD may closely resemble those present in OCD, both phenotypically and perhaps to a lesser extent in terms of the distress, interference and ego-dystonia associated with these experiences. While more rigorous research is required to further investigate these phenomena, the existing literature highlights the importance of screening for the presence of comorbid OCD, including the development of appropriate tools, in order to ensure that appropriate interventions are not withheld.

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**Major Research Project**

**SECTION B**

**A comparison of obsessive thoughts and compulsive behaviours in adults with obsessive compulsive disorder (OCD) and autistic spectrum disorder (ASD)**

Word Count: 8000 (16)

A thesis submitted in partial fulfilment of the requirements of Canterbury Christ Church University for the degree of Doctor of Clinical Psychology.

July 2013

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### Abstract

**Background:** Questions have been raised as to whether the patterns of thoughts and behaviours experienced by individuals with autistic spectrum disorders (ASD) can be indicative of comorbid obsessive compulsive disorder (OCD). **Objective:** The current study aimed to compare the experiences of adults with ASD or OCD and healthy controls (HC) in terms of the symptoms experienced and the associated emotions and responses. Associations between autistic traits and OCD severity were explored. **Design:** A cross-sectional design utilising MANOVA, ANOVA and correlation was employed. **Methods:** Eighteen participants with ASD, 20 with OCD and 19 healthy controls completed self-report measures and interviews assessing IQ, comorbid diagnoses, OCD symptoms, autistic traits and emotions and responses associated with obsessional thoughts. **Results:** Participants with ASD scored significantly higher than healthy controls in terms of OCD severity and also number of obsessions and compulsions and associated distress. While the OCD and ASD groups did not differ significantly on OCD severity, the OCD group reported significantly higher levels of sadness, worry, shame, guilt and disapproval triggered by obsessions. The ASD and healthy control groups were largely comparable on these factors. Associations were found between OCD severity and particular domains which are typically impaired in ASD, including social skills, attention switching, communication and imagination. **Conclusions:** Findings suggest that OCD symptoms may be common and a source of distress in individuals with ASD, thus perhaps warranting psychological intervention. Further research into the exact nature of this distress and how this can be assessed is required.

## **Introduction**

### **The Obsessive-Compulsive Spectrum**

The obsessions and compulsions characteristic of obsessive compulsive disorder (OCD; APA, 2000) appear similar to patterns of thoughts and behaviours present in other disorders including tic, impulse-control and eating disorders. These parallels, coupled with familial, genetic and neuroimaging studies (Bartz & Hollander, 2006) have led to suggestions that these disorders may be conceptualised as falling on an obsessive-compulsive spectrum (OCS; Hollander, 2005). While this has been the subject of debate (Abramowitz et al., 2009), the possible similarities are recognised in DSM-V's new category of 'obsessive compulsive and related disorders' (APA, 2013).

According to the OCS model, disorders would be located on a compulsivity-impulsivity dimension, with disorders characterised by behaviours aimed at reducing anxiety/minimizing harm at one end and disorders where behaviours are motivated by pleasure-seeking at the other (Bartz & Hollander, 2006).

### **Obsessions and Compulsions in Autistic Spectrum Disorders**

It has been proposed that autistic spectrum disorders (ASD) may also be on the OCS (Hollander & Zohar, 2004, as cited in Abramowitz et al, 2009). This has been the subject of additional debate, particularly regarding whether patterns of thoughts and behaviours observed in ASD can be conceptualised as 'obsessions' and 'compulsions'. Baron-Cohen (1989) cautions against using these terms to describe the experiences of this population, suggesting the restricted interests and repetitive behaviours (RRBs) included in the triad of impairments necessary for ASD diagnosis (APA, 2000) differ from obsessions and compulsions characteristic of

OCD. In contrast, others have argued these phenomena can be indicative of OCD and should be diagnosed as such (Leekham, Prior & Uljarevic, 2011).

Estimated rates of comorbid OCD in adults with ASD vary widely from 3.7% (Hutton et al., 2008) to 72.2% (Lai et al, 2011). This variation may partly be due to difficulty distinguishing RRBs from obsessions and compulsions (Matson & Dempsey, 2009) and in some cases diagnostic overshadowing may prevent consideration of a secondary diagnosis.

One avenue for exploring whether obsessive-compulsive phenomena in individuals with ASD are indicative of comorbid OCD, RRBs or obsessions and compulsions located elsewhere from OCD on the OCS impulsivity-compulsivity dimension, is through direct comparison of the experiences of individuals with OCD and ASD.

### **Comparison of obsessions and compulsions in OCD and ASD.**

Studies comparing patterns of apparent obsessive-compulsive symptoms reported by adults with OCD and ASD are limited and results vary.

Using the Yale-Brown Obsessive Compulsive Scale (Y-BOCS; Goodman et al., 1998a,b) McDougle et al. (1995) reported profiles of obsessions and compulsions differed significantly between adults with ASD and OCD. Using discriminant analysis seven categories of obsessions and compulsions which correctly categorised 85% of participants were identified. However, reported differences may be explained by significant differences in IQs between groups. Furthermore, 30% of ASD participants were non-verbal which may account for the lower frequency of obsessions reported by this group.

In contrast, Russell et al. (2005) reported comparable symptom profiles in adults with ASD and OCD, all of whom had IQs above 70. Discriminant analysis

found group membership was best predicted by a single obsession and compulsion, although overall frequencies of both obsessions and compulsions were significantly higher in the OCD group. Like McDougle et al.'s study, Russell et al.'s work was limited by a lack of control group to examine whether the frequencies and patterns of obsessions and compulsions displayed by individuals with ASDs differed from healthy controls. Furthermore, only 58% of the ASD sample in this study were diagnosed using structured diagnostic interviews.

While failing to provide information regarding how secondary OCD diagnoses were made, Cath, Ran, Smit, Balkom and Comijs (2008) directly compared the obsessive-compulsive symptoms of adults with OCD (n=12), comorbid ASD and OCD (n=6) and controls (n=12). No differences were found between the OCD and the ASD plus comorbid OCD groups on any of the symptoms factors of the Y-BOCS. However, small sample sizes may have led to insufficient power to detect any differences. Furthermore, the comorbid ASD group were not identified using a validated diagnostic tool and only half scored above a clinical cut-off on a measure of autistic traits. Further research involving larger, IQ-matched samples with clinically confirmed diagnoses and including non-clinical comparison groups is therefore required in order to compare obsessive-compulsive symptoms patterns in ASD and OCD.

#### **Distress and ego-dystonia: Diagnostic criteria and theoretical models of OCD.**

While obsessive-compulsive symptoms experienced by individuals with ASD may appear similar to those reported by individuals with OCD, it has been argued these symptoms may not be sufficient to meet diagnostic criteria or fit with theoretical models of OCD.



OCD diagnostic criteria (APA, 2000; WHO, 1992) describe the presence of obsessions and/or compulsions occupying more than one hour daily or causing distress/impaired functioning. Obsessions are defined as being recurrent and experienced as intrusive, inappropriate or distressing. Cognitive models of OCD (Salkovskis, 1989; Rachman, 1998) conceptualise compulsions as responses which are intended to reduce the anxiety caused by obsessions and their appraisal (e.g. as indicating an individual may be responsible for harm). Inherent to such theories is the idea that obsessions produce feelings of anxiety/distress which an individual wishes to reduce. While compulsions may offer some temporary relief, they also contribute to the maintenance of symptoms by preventing the testing of appraisals of obsessions.

While diagnostic criteria and conceptual models of OCD emphasise the ego-dystonic and distressing nature of symptoms this has been hypothesized to be a key area of distinction between the symptoms of OCD and the experiences of individuals with ASD. It has been suggested that the restricted interests or obsessions present in individuals with ASD can be a source of enjoyment rather than distress and that compulsions or repetitive behaviours are not performed in an attempt to reduce the distress resulting from obsessive thoughts (e.g. Baron-Cohen, 1989; Ivarsson & Merlin, 2008). According to Ruta, Mugno, D'Arrigo, Vitiello and Mazzone (2010, p18), "individuals with ASD tend not to show distress associated with their fixed beliefs and do not perform rituals to alleviate anxiety." Such assertions also raise questions as to where ASD would fall on a proposed OCS impulsivity-compulsivity dimension.

While the potentially ego-systonic nature of obsessions and compulsions in ASD has been the subject of speculation, there has been limited empirical research to support these assumptions.

In addition to the symptom checklist of the Yale-Brown Obsessive Compulsive Scale (Y-BOCS; Goodman et al., 1989a,b), two studies have compared adults with ASD and OCD using this measure's severity scale. Russell et al. (2005) found significantly higher severity scores in their OCD group compared to their ASD group. Cath et al. (2008) also reported that severity in adults with ASD and comorbid OCD was lower than individuals with OCD but higher than healthy controls.

Limited conclusions can be drawn from the findings outlined above regarding the distress or ego-dystonia associated with obsessive-compulsive symptoms. By reporting total severity scores, studies have grouped together items asking specifically about distress and those assessing resistance, control, interference with functioning and time occupied. While increased duration/frequency of these experiences elevates severity scores, they do not indicate whether experiences are sources of pleasure or distress.

Few studies have separated these components or examined distress/ego-dystonia specifically. McDougle et al. (1995) reported 23% of verbal ASD participants described trying to suppress obsessive thoughts or resist compulsions, leading to conclusions these experiences were unwanted/distressing. Cath et al. (2008) attempted to examine ego-dystonia directly by designing four questions to assess the extent to which symptoms were experienced as excessive/unreasonable, strange/abnormal and inappropriate and how much the individual felt they needed to control them. Contrary to their expectations, no differences were found between adults with OCD and those with ASD and apparent comorbid OCD. No comparisons

to healthy controls were made. The extremely small sample sizes in this study may have resulted in insufficient power to detect any existing differences. Furthermore, as previously outlined, ASD diagnoses were not confirmed using validated diagnostic tools and only 50% of the ASD group (three individuals) scored above the clinical cut-off on a measure of autistic traits.

#### **Further evidence: Autistic traits in OCD.**

Inferences regarding the presence of ego-dystonic obsessions and compulsions in ASD have also been drawn by studies examining the presence of autistic traits in individuals with OCD.

Using the Autism Quotient ASD screening questionnaire (AQ; Baron-Cohen et al., 2001) elevated rates of autistic traits have been reported in adults with OCD, with 4-4.6% scoring above the cut-off indicative of clinically significant autistic traits (Pertusa et al., 2012, and Anholt et al., 2010, respectively). Rates of autistic traits have also been found to be significantly higher in adults with OCD compared to healthy controls (Anholt et al., 2010). Furthermore, 2.7-4.7% of samples of adults with OCD later received diagnoses of Asperger's syndrome (Bejerot, Nylander & Lindstrom, 2001; La Salle et al., 2001). Bejerot et al. (2001) argued this indicates the presence of ego-dystonic obsessions and compulsions in ASD, based on the fact these undiagnosed individuals had been seeking support for OCD. Using the AQ, the presence of autistic traits was also found to be significantly correlated with Y-BOCS severity scores (Anholt et al., 2010; Cath et al., 2008).

#### **Rationale for Current Study**

The current study aimed to compare the presence of obsessions and compulsions in high-functioning adults with ASD to adults with OCD and a healthy non-clinical control group. In addition to comparing the patterns of apparent

obsessions and compulsions, this study aimed to further explore the emotions associated with experiences of obsessions and responses to their occurrence in order to explore whether or not they are ego-dystonic in individuals with ASD and whether, in keeping with cognitive-behavioural models, compulsions occur in response to such obsessions in this group. The possible presence of ego-dystonic obsessions/compulsions in ASD may have implications in relation to understandings of these experiences and whether they may indicate the presence of comorbid OCD.

In line with suggestions that presence of autistic traits may correlate with OCD severity, autistic traits will be assessed and the association with symptom severity will be explored. In contrast to previous studies, deficits classed as autistic traits will be examined separately and the possibility of the association also existing in non-clinical populations will be explored. Again, such findings may have clinical implications in terms of adaptations to interventions for individuals who have OCD and who may also display high level of ASD traits.

#### **Research questions.**

- Do the number and types of obsessions and compulsions reported vary between adults with high-functioning ASD, OCD and healthy controls?
- Do the severity of obsessions and compulsions and the associated emotions and responses differ for individuals with ASD compared to those with OCD and healthy controls? Is there evidence that obsessions experienced by individuals with ASD may be ego-dystonic/distressing?
- Do OCD severity scores and associated distress vary according to the presence of autistic traits?

## **Method**

### **Design**

A quantitative, cross-sectional design was employed to compare the experiences of individuals with ASD, OCD and healthy controls (HC).

A correlational design was used to explore associations between ASD traits and OCD severity.

### **Participants**

#### **Inclusion/exclusion criteria.**

Participants had to be 18 years or older and have a clinically confirmed diagnosis of OCD or ASD. HC participants were required to have never been given a diagnosis of either. All participants had to be able to give informed consent. Individuals with learning disabilities or who did not speak English were excluded. Diagnostic uncertainty or comorbid psychotic disorders were exclusion criteria.

#### **Recruitment.**

OCD and ASD participants were recruited through NHS clinics in south-east England. Potential participants were identified and contacted by clinic staff and given an invite letter and information sheet (Appendices G and H). Individuals were asked to contact the chief investigator if they wished to participate. Additional participants were recruited through third-sector organisations using posters and online advertisements (Appendix I).

HC participants were recruited through advertisements on community noticeboards and social media websites (Appendix J).

**Sample.**

Eighteen participants with ASD, 20 with OCD and 19 HC, aged 18-68 years, chose to participate. Within the ASD group, 16 participants had diagnoses of Asperger's Syndrome (AS) and two had diagnoses of high-functioning Autism (HFA).

**Measures****Mini International Neuropsychiatric Interview (MINI).**

The MINI diagnostic interview (Sheehan et al., 1998; Appendix K) was used to assess the presence of comorbid Axis I disorders. Compared to the SCID, the MINI has good construct validity, with kappa values ranging from .50-.90 ( $p > .05$ ) for all Axis I disorders. Specificities and negative predictive value were .85 or above for the majority of diagnoses and sensitivities were .70 or greater. The MINI has good test-retest and excellent inter-rater reliabilities (Sheehan et al., 1998) and has previously been used with individuals with OCD and ASD (Pertusa et al., 2012).

**National Adult Reading Test (NART).**

The NART (Nelson, 1982; Appendix L), a list of 50 words with irregular grapheme-phoneme correspondence which individuals are asked to read aloud, was used as a proxy of intellectual functioning. While commonly used to estimate premorbid functioning, NART estimated IQs correlate strongly with concurrent Wechsler Adult Intelligence Scale (WAIS-III) IQs. Furthermore, NART-estimated IQs were found to correlate more strongly with WAIS-III results than Wechsler Test of Adult Reading (WTAR) IQs in healthy controls (Mathias et al., 2007). NART-estimated IQs have also been found to be more strongly correlated with WAIS assessed IQs than IQs estimated using demographic variables (Bright, Jaldow & Kopelman, 2002). The NART has also been used as an indicator of IQ in individuals with ASD (Beacher et al., 2012a,b; Radulescu et al., 2012)

**Yale-Brown Obsessive Compulsive Scale (Y-BOCS).**

The Y-BOCS (Goodman et al., 1989a,b; Appendix M) was used to assess obsessive-compulsive symptoms. This measure consists of a 63-item symptom scale describing commonly reported obsessions and compulsions, scored as being present or absent. Symptoms fall into eight categories of obsessions; aggressive, contamination, sexual, hoarding/saving, religious, symmetry/exactness, somatic, and miscellaneous, and seven categories of compulsions; cleaning/washing, checking, repeating, counting, ordering/arranging, hoarding/saving and miscellaneous.

Ten severity items, rated on five-point Likert scales, assess time occupied, interference, distress, resistance and level of control in relation to obsessions and compulsions. Total severity scores range from 0-40. The severity scale has been found to have excellent internal consistency and inter-rater reliability in clinical and non-clinical samples (Frost, Steketee, Krause, & Trepanier, 1995; Goodman et al., 1989a). Convergent validity with other clinician-rated OCD scales is good (Goodman et al., 1989b) and excellent test-retest reliability in clinical samples has been reported for both the symptom and severity scales (Kim et al., 1990).

The Y-BOCS can be completed as a self-report measure or a clinician-administered semi-structured interview. The interview version was employed in this study to allow clarification of symptoms, thus ensuring only experiences meeting the definitions of obsession and compulsions were recorded.

The Y-BOCS is “widely acknowledged as the gold standard measure of OCD symptom severity” (Deacon & Abramowitz, 2005, p573) and has been used with adults with ASD (Cath et al., 2008; McDougle et al., 1995; Russell et al., 2005).

**Adult Autism Spectrum Quotient (AQ) and Empathy Quotient (EQ).**

Autistic traits were assessed using the AQ (Baron-Cohen et al., 2001; Appendix N) and EQ (Baron-Cohen & Wheelwright, 2004; Appendix O).

While not a diagnostic tool, the 50-item, self-report AQ can be used as a screening measure. Responses are scored using a dichotomous scale, giving a total of 0-50, with scores of 32 or above indicating clinically significant levels of ASD traits. The AQ also yields five subscale scores; social skills, attention switching, attention to detail, communication and imagination.

The AQ has been reported to have excellent face validity, with individuals with ASD scoring significantly higher than controls on all subscales (Baron-Cohen et al., 2001). The measure also has good test-retest reliability ( $r = .7$ ,  $p = .002$ ) and moderate-high internal consistency, with Cronbach's alphas for subscales ranging between .63 and .77.

The 60-item, self-report EQ is designed to assess empathy, which can be defined as an emotional response to the emotions of another. It involves understanding other's emotions using theory of mind; a skill proposed to be deficient in individuals with ASD (Baron-Cohen, 1995).

The EQ comprises of 40 items relating to empathy and 20 'filler'/control items included to distract from this focus. The four-point Likert scale for each item yields scores of 0-2, giving a total score of 0-80. A score of under 30 is indicative of an empathy deficit. This measure has good construct validity, with adults with ASD scoring significantly lower than controls, EQ scores being strongly negatively correlated with AQ scores (Baron-Cohen & Wheelwright, 2004) and moderately correlated with the empathic concern and perspective taking subscales of the Interpersonal Reactivity Index (Lawrence, Shaw, Baron-Cohen & David, 2004). The



EQ has good test-retest reliability ( $r = .835$ ,  $p = 0.001$ ; Lawrence et al., 2004) and excellent item reliability using Rasch analysis (Allison, Baron-Cohen, Wheelwright, Stone & Muncer, 2011).

### **Cognitive Intrusions Questionnaire (CIQ).**

The CIQ (Freeston, Ladouceur, Thibodeau, & Gagnon, 1991; Appendix P) was used to assess the emotions and responses associated with obsessive thoughts. The CIQ was developed to explore interpretations of cognitive intrusions in individuals with OCD, and healthy controls and has since been used to compare obsessive thoughts and worry and links between appraisal and response (Freeston et al., 1991, 1992; Freeston & Ladouceur, 1993; Langlois, Freeston & Ladouceur, 2000). The 42 items, rated on nine-point Likert scales, cover responses to intrusions, (e.g. distraction and attempts to neutralize the thought), effectiveness of responses, associated emotions (e.g. sadness, guilt, disapproval) and form of intrusion (e.g. image or urge). While not producing a total score, this measure has been used to explore links between appraisals and responses and also to explore differences between individuals with different diagnoses.

### **Procedure and Ethical Considerations**

The study was given a favourable ethical opinion by an NHS Local Research Ethics Committee (Appendix Q) and was approved by the Research and Development department of the relevant trust (Appendix R). Prior to starting the study, service users with ASD or OCD and healthy controls were consulted regarding information sheets and procedures.

Potential participants received study information by post or through advertisements. Upon contacting the chief investigator, they were provided with an

opportunity to ask questions and meetings were arranged for those wishing to pursue participation.

At testing, participants were provided with information regarding session structure and measures to be completed. The sensitive nature of some questions was explained and participants were informed that while the data they provided would be confidential, an exception would be if they were to disclose information indicating a risk to themselves or another. Participants were informed they could withdraw at any point and choose not to answer any questions. For participants who had recently been assessed within the clinic or who had taken part in the clinic's own research studies, permission was sought to obtain any relevant measures already completed to avoid unnecessary repetition. This information was also provided in a written consent form (Appendix S). Local procedures were followed when meeting participants on NHS premises.

Following completion of the MINI, Y-BOCS and NART, participants were asked to complete the AQ, EQ and CIQ. Participants were given the option of completing these questionnaires independently with the chief investigator available to offer support/clarification, or having items read to them. Definitions of obsessions and compulsions were provided before commencing the Y-BOCs and repeated as required. Participants' Y-BOCS responses were utilised to facilitate identification of a thought which could be used as a frame of reference when completing the CIQ.

Following completion, participants were offered the opportunity to discuss any questions or concerns and details of local/national ASD and OCD organisations were made available. Participants were paid £15 for their attendance. Data were anonymised through the use of participant identification numbers and stored securely.

## Analysis

All analysis was completed using IBM SPSS version 20.0. Prior to analysis, assumptions underlying parametric statistics were explored. Normality of distributions were explored using histograms, skewness, kurtosis and Kolmogorov-Smirnov tests. Levene's tests were used to explore the assumption of homogeneity of variance.

Not all measures met the assumptions for parametric statistics for each group. While transformations can be utilised, their use has also been the subject of debate with Games (1984) proposing they can impact on validity of results and thus their benefits may be outweighed by their costs. Furthermore, normality can be difficult to determine in small samples (Games, 1984) and Glass, Peckham and Sanders (1972) instead recommended the use of robust tests such as the F-test in ANOVAs. A further alternative is the use of bootstrapping. Bootstrapping allows estimation of the sampling distribution by drawing multiple samples from the sample data. The statistic of interest is calculated for each sample, allowing the estimation of the sampling distribution of the statistic, and the related standard error is estimated using the standard deviation of the distribution created by the multiple samples. In addition to being a robust technique that is beneficial when parametric assumptions are not met, the use of bootstrapping has also been suggested to be beneficial with small samples (Field, 2012, Wilcox, 2005). For the analyses detailed below, bootstrapping was employed using bias corrected and accelerated confidence intervals [BCa CI] and 10000 samples (Field, 2012). If zero is not included within the 95% CI, then the probability of the null hypothesis being true is lower than .05.

MANOVAs and one-way independent ANOVAs were used to make between-group comparisons. Welch's test was used when the assumption of homogeneity of

variance was violated (as indicated by significant Levene's tests). Planned contrasts were used when the nature of any differences had been predicted. Where no predictions had been made, post hoc comparisons were made. Based on the small, slightly unequal sample sizes, Gabriel's pairwise test procedure was used. When group variances were unequal, the Games-Howell procedure was used (Field, 2009). Bootstrapped Pearson's correlations were used to explore any association between OCD severity and the presence of autistic traits.

## **Results**

### **Participant Demographics**

Participant demographics are provided in Table 1.

Table 1

*Participant demographics*

	<b>HC</b> <i>n</i> =19	<b>ASD</b> <i>n</i> =18	<b>OCD</b> <i>n</i> =20	<b>Total</b> <i>n</i> =57
<b>Gender: n</b>				
Male	7	15	10	32
Female	12	3	10	25
<b>Age (years)</b>				
Mean	35.68	38.83	39.50	38.02
SD	10.08	12.09	13.16	11.77
Median	33.00	41.50	37.50	34.00
Range	26-62	18-61	21-68	18-68
<b>Comorbid diagnoses (MINI)</b>				
n				
Major depression (recurrent)	0	1	0	1
Panic	0	1	0	1
Agoraphobia	0	3	0	3
Social phobia	0	2	1	3
OCD	0	10	20	30
Dysthymia	0	0	2	2
<b>NART FSIQ</b>				
Mean	112.59	113.31	112.36	112.75
SD	5.43	13.24	7.83	9.12
Median	112.00	116.96	112.00	112.00
Range	103.32-123.16	88.44-130.60	97.12-126.88	88.44-130.60

One-way ANOVAs revealed age and full scale IQ (FSIQ) did not differ significantly between groups,  $F(2,54)=0.57$ ,  $p=.571$ ,  $\omega^2=0.02$  and  $F(2,50)=0.05$ ,  $p=.952$ ,  $\omega^2=0.04$ , respectively. Fisher's exact test revealed a significant difference in the proportions of male and female participants in each group ( $p=.012$ ). However, independent factorial ANOVAs and MANOVAs revealed gender did not have a significant effect on or a significant interaction with diagnosis for AQ or EQ total score, Y-BOCS severity score, negative emotions triggered by obsessions or responses to obsessions (Appendix T).

### **Do the Number and Types of Obsessions and Compulsions Reported Vary Between Adults with OCD, ASD and Healthy Controls?**

Unfortunately symptom data were unavailable for the majority of OCD participants and therefore insufficient data were available to run a discriminant analysis as planned. Comparisons were therefore made between ASD and HC participants only.

Seventeen ASD participants reported both obsessions and compulsions and one reported experiencing neither obsessions nor compulsions. Of the healthy control group, 12 reported obsessions and compulsions, five reported obsessions only and two reported experiencing neither.

Participants with ASD were found to have more obsessions and compulsions ( $M=9.22$ ,  $SD=5.04$  and  $M=4.61$ ,  $SD=2.57$  respectively) compared to healthy controls ( $M=3.16$ ,  $SD=2.17$  and  $M=1.58$ ,  $SD=1.71$ ). These differences ( $-6.06$ ,  $BCa$  95%CI  $[-8.70$  to  $-3.53]$  and  $-3.03$ ,  $BCa$  95%CI  $[-4.46$  to  $-1.57]$ ) were both significant,  $t(22.82)=-4.71$ ,  $p<.001$ ,  $d=1.58$ , and  $t(35)=-4.80$ ,  $p<.001$ ,  $d=1.40$  respectively.

Table 2 shows the number of ASD and HC participants reporting obsessions and compulsions in each symptom category.

Table 2

*ASD and HC participants endorsing each category of obsessions and compulsions.*

	ASD <i>n</i>	Control <i>n</i>	Fisher's Exact Test ( <i>p</i> values)	Effect size (Odds ratio)
<b>OBSESSIONS</b>	17	17	.521	-
Aggressive	14	13	.395	-
Contamination	12	3	.002	10.67
Sexual	5	0	.020	<sup>a</sup>
Hoarding	6	0	.008	<sup>a</sup>
Religious	13	3	.001	13.97
Symmetry	12	5	.016	5.58
Somatic	7	8	.554	-
Miscellaneous	15	11	.091	-
<b>COMPULSIONS</b>	17	12	.025	9.93
Cleaning	12	4	.006	7.50
Checking	14	7	.014	6.0
Repeating	3	1	.281	-
Counting	3	2	.473	-
Ordering	11	5	.035	4.4
Hoarding	3	0	.105	-
Miscellaneous	11	8	.204	-

<sup>a</sup>Odds ratios unable to be calculated due to presence of zero frequencies in some cells.

Fisher's exact tests revealed significant associations between group and whether contamination, sexual, hoarding, religious and symmetry obsessions were experienced. Significant associations between group and the presence of compulsions, specifically cleaning, checking and ordering, were also found. Occurrence of these symptoms was found to be more probable in the ASD group compared to controls (see Table 2 for *p* values and odds ratios).

### **Do the Severity of Obsessions and Compulsions and the Associated Emotions and Responses Differ Between Individuals with ASD and OCD?**

A one-way independent ANOVA revealed a significant effect of group on Y-BOCS severity score,  $F(2,52)=48.82$ ,  $p<.001$ ,  $\omega^2=.63$  Planned orthogonal contrasts

revealed significantly higher severity scores for the ASD ( $M=20.56$ ,  $SD=7.60$ ) and OCD groups ( $M=23.89$ ,  $SD=5.64$ ) compared to HC ( $M=5.32$ ,  $SD=4.84$ ),  $t(52)=9.75$ ,  $p<.001$ ,  $r=.80$ . No significant difference was found between mean severity scores for participants with ASD and OCD, as confirmed by a bootstrapped comparison, although a medium effect size was found (mean difference=  $-3.33$ , BCa CI [ $-8.36$ ,  $1.69$ ],  $p=.288$ ,  $d=.50$ ).

Distress scores were calculated by combining the two Y-BOCS severity items asking specifically about distress caused by obsessions and compulsions, with a score of zero indicating no distress, through to a score of eight indicating extreme distress. Unfortunately these scores were unavailable for the majority of OCD participants, but an independent-samples t-test found distress to be significantly higher in the ASD ( $M=4.17$ ,  $SD=0.96$ ) compared to HC group ( $M=1.53$ ,  $SD=0.96$ ),  $t(25.25)=-5.39$ ,  $p<.001$  (2-tailed),  $d=1.80$ , 95% BCa CI [ $-3.60$ ,  $-1.57$ ]. No healthy controls reported symptoms occupying more than one hour daily. In comparison, 12 ASD participants (66.7%) reported obsessive-compulsive symptoms occupying over one hour daily.

Items from the CIQ exploring the presence of negative emotions triggered by obsessions are presented in Table 3, along with the mean response for each group. Each item is scored on a nine-point Likert scale from one (not at all) to 9 (extremely). A MANOVA was used to explore the effect of group on negative emotions. Using Pillai's trace, there was a significant effect of group on negative emotions triggered by obsessions,  $V=0.60$ ,  $F(14,98)=3.00$ ,  $p=.001$ . Separate univariate ANOVAs revealed significant effects of group on the extent participants experienced sadness, worry, guilt, disapproval or shame or disapproved of the content or presence of their obsessions (see Table 3 for  $F$ ,  $p$  and  $\omega^2$  values).



Table 3.

*Emotions triggered by obsessions (mean (S.D))*

	<b>HC</b> <i>n</i> =19	<b>ASD</b> <i>n</i> =18	<b>OCD</b> <i>n</i> =20	<b>F</b> (2, 57)	<b>Effect size</b> ( $\omega^2$ )
How <b>sad</b> or <b>unhappy</b> does this thought make you feel?	4.37(2.06)	4.78(2.16)	6.90(2.43)	7.29**	.18
How <b>worried</b> does this thought make you feel?	4.68(1.97)	6.00(2.28)	7.65(1.60)	11.27***	.26
How <b>guilty</b> does this thought make you feel?	3.00(1.73)	3.33(2.35)	5.75(2.79)	7.03 <sup>a</sup> **	.20
How much do you <b>disapprove</b> that the thought enters your mind?	4.37(2.41)	4.06(2.13)	7.15(1.81)	12.47***	.29
How <b>ashamed</b> does this thought make you feel?	2.63(2.01)	3.44(2.83)	5.85(2.82)	8.23***	.20
To what extent does the thought's <b>content disturb</b> you?	4.11(2.56)	5.61(2.36)	6.50(2.40)	4.78*	.12
To what extent does the thought's <b>presence disturb</b> you?	3.68(2.36)	4.72(2.22)	6.75(2.20)	9.32***	.23

<sup>a</sup> Welch's test (2, 34.62)\*\*\*  $p \leq .001$  \*\*  $p \leq .01$  \*  $p \leq .05$  NS  $p > .05$ 

Bootstrapped post-hoc comparisons were carried out and results are displayed in Table 4.

Table 4.

*Bootstrapped post-hoc comparisons for negative emotions triggered by obsessions*

Item	Comparison	Mean Difference	Standard Error	95% BCa Confidence Interval <sup>a</sup>	
				Lower	Upper
<b>Sad<sup>b</sup></b>	HC vs ASD	-.409	.713	-1.840	.992
	HC vs OCD	-2.532*	.710	-3.872	-1.210
	ASD vs OCD	-2.122*	.762	-3.502	-.710
<b>Worried<sup>b</sup></b>	HC vs ASD	-1.316*	.657	-2.655	-.090
	HC vs OCD	-2.966*	.559	-4.000	-1.982
	ASD vs OCD	-1.650*	.595	-2.809	-.445
<b>Guilty<sup>c</sup></b>	HC vs ASD	-.333	.649	-1.569	.872
	HC vs OCD	-2.750*	.745	-4.117	-1.459
	ASD vs OCD	-2.417*	.814	-3.950	-.802
<b>Disapprove<sup>b</sup></b>	HC vs ASD	.313	.735	-1.139	1.840
	HC vs OCD	-2.782*	.674	-4.108	-1.317
	ASD vs OCD	-3.094*	.632	-4.283	-1.789
<b>Ashamed<sup>b</sup></b>	HC vs ASD	-.813	.819	-2.404	.796
	HC vs OCD	-3.218*	.762	-4.618	-1.823
	ASD vs OCD	-2.406*	.927	-4.085	-.722
<b>Content disturbs<sup>b</sup></b>	HC vs ASD	-1.506	.780	-3.069	.239
	HC vs OCD	-2.395*	.785	-3.919	-.609
	ASD vs OCD	-.889	.758	-2.408	.603
<b>Presence disturbs<sup>b</sup></b>	HC vs ASD	-1.038	.749	-2.532	.486
	HC vs OCD	-3.06*	.716	-4.605	-1.548
	ASD vs OCD	-2.028*	.695	-3.327	-.562

<sup>a</sup> Based on 1000 bootstrap samples<sup>b</sup> Gabriel's procedure<sup>c</sup> Games-Howell procedure\*  $p < .05$ 

Participants with OCD experienced significantly higher levels of sadness, worry, guilt, disapproval and shame and were more disturbed by the content and

presence of their obsessions compared to healthy controls. In comparison to controls, the negative emotions experienced by participants with ASD did not differ significantly, with the exception of worry, which was significantly higher in the ASD group. When comparing participants with OCD and ASD, all negative emotions explored were significantly stronger within the OCD group with the exception of feeling disturbed by the content of thoughts, a factor on which both groups were comparable.

Means scores for CIQ items exploring the frequency of various responses to obsessive thoughts are presented in Table 5. Items are rated on scales of one (never) through to nine (always). A MANOVA was used to explore the effect of group on responses to obsessions. Using Pillai's trace, there was a significant effect of group on the responses employed when experiencing obsessions,  $V=0.683$ ,  $F(20, 92)=2.39$ ,  $p=.003$ . Separate univariate ANOVAs revealed significant effects of group on the extent to which participants did not respond to obsessions and let them pass on their own accord, sought reassurance, replaced thoughts and told themselves to "stop" (see Table 5 for  $F$ ,  $p$  and  $\omega^2$  values).

Table 5.

*Responses to obsessions (mean (S.D))*

<b>What do you normally do when the thought occurs?</b>	<b>HC n=19</b>	<b>ASD n=18</b>	<b>OCD n=20</b>	<b>F (2, 54)</b>	<b>Effect size (<math>\omega^2</math>)</b>
I don't do anything, it goes of its own accord	5.16 (2.77)	4.61 (2.77)	3.20 (1.67)	4.29 <sup>a*</sup>	.08
I reassure myself by saying it doesn't mean anything	3.79 (2.25)	3.39 (2.48)	4.30 (2.41)	0.70 <sup>NS</sup>	.01
I seek reassurance from someone else	2.11 (1.66)	3.83 (2.66)	4.10 (2.55)	5.37 <sup>b**</sup>	.10
I do something in my mind or in action to neutralize the thought	4.42 (2.67)	5.94 (2.82)	5.35 (2.80)	1.44 <sup>NS</sup>	.02
I think it through	4.53 (2.09)	4.72 (2.11)	5.15 (2.56)	0.39 <sup>NS</sup>	.02
I try to replace the thought by another	4.37 (2.39)	2.83 (1.95)	4.53 (2.25)	3.74 <sup>*</sup>	.09
I try to distract myself with things around me	4.11 (2.00)	3.61(2.36)	4.25 (1.52)	0.58 <sup>NS</sup>	.02
I throw myself into some absorbing activity	3.84 (2.46)	2.44 (1.72)	3.20 (1.77)	2.24 <sup>NS</sup>	.04
I say "stop" to myself	2.74 (1.88)	2.22 (1.44)	4.10 (2.57)	3.88 <sup>c*</sup>	.10
Other	1.74 (1.91)	3.44 (3.13)	3.45 (3.27)	3. <sup>11dNS</sup>	.04
<sup>a</sup> Welch's test (2, 32.71)	<sup>b</sup> Welch's test (2, 33.99)	<sup>c</sup> Welch's test (2, 35.09)			
<sup>d</sup> Welch's test (2, 33.53)					
*** $p \leq .001$ ** $p \leq .01$	* $p \leq .05$	<sup>NS</sup> $p > .05$			

As can be seen from Table 5 the response reported to be used most frequently in healthy controls was doing nothing in response to obsessions and simply letting them pass. In contrast, attempting to neutralise the thought in mind or in action were reported to be the most frequently used responses by participants with ASD and OCD. Details of the 'other' responses reported by each group are presented in Appendix U.

Bootstrapped post-hoc comparisons were carried out for the four significant ANOVAs and are presented in Table 6.

Table 6.

*Bootstrapped post-hoc comparisons for responses to obsessions*

Comparison	Mean Difference	Standard Error	95% BCa Confidence Interval <sup>a</sup>	
			Lower	Upper
<b>Do nothing<sup>c</sup></b>				
HC vs ASD	.547	.932	-1.318	2.249
HC vs OCD	1.958*	.774	.409	3.408
ASD vs OCD	1.411*	.770	.001	2.941
<b>Seek reassurance<sup>c</sup></b>				
HC vs ASD	-1.728*	.744	-3.271	-.307
HC vs OCD	-1.995*	.671	-3.281	-.662
ASD vs OCD	-.267	.853	-1.979	1.423
<b>Replace thought<sup>b</sup></b>				
HC vs ASD	1.535*	.710	.189	2.878
HC vs OCD	-.382	.754	-2.000	1.037
ASD vs OCD	-1.917*	.685	-3.265	-.569
<b>Say "stop"<sup>c</sup></b>				
HC vs ASD	.515	.559	-.504	1.716
HC vs OCD	-1.363	.737	-2.824	.056
ASD vs OCD	-1.878*	.659	-3.203	-.608

<sup>a</sup> Based on 1000 bootstrap samples

<sup>b</sup> Gabriel's procedure

<sup>c</sup> Games-Howell procedure

\*  $p < .05$

As demonstrated by the results presented in Table 6, healthy controls and participants with ASD both responded to obsessions by doing nothing significantly more frequently than participants with OCD. HC and ASD groups did not differ

significantly on their use of this response. However, while healthy controls reported seeking reassurance significantly less often than participants with ASD or OCD, the two clinical groups not differ significantly with regards to their use of this response. Interestingly, participants with ASD reported less frequent attempts to replace obsessive thoughts than either healthy controls or participants with OCD, though HC and OCD groups did not differ significantly with their use of this response. Finally, saying “stop” was reported to be used more frequently by the OCD compared to ASD group, but no other pairwise comparisons were significant for this variable.

### **Do OCD Severity Scores Vary According to the Presence of Autistic Traits?**

Mean EQ and AQ total scores and AQ subscale scores are presented in

Table 7.

Table 7.

*AQ and EQ scores by group (mean (S.D))*

	<b>ASD</b>	<b>OCD</b>	<b>HC</b>
<b>AQ</b>	<i>n=18</i>	<i>n=20</i>	<i>n=19</i>
Total Score	37.56(6.52)	17.90(8.33)	13.74(6.58)
Social Skills	7.72(2.56)	2.80(2.26)	1.84(1.86)
Attention Switching	8.89(1.53)	5.05(2.09)	3.53(2.50)
Attention to Detail	6.61(2.23)	5.20(2.55)	4.63(1.01)
Communication	8.11(1.75)	2.20(2.38)	2.11(1.94)
Imagination	6.22(1.96)	2.65(2.08)	1.63(1.34)
<b>EQ</b>	<i>n=18</i>	<i>n=19</i>	<i>n=19</i>
Total Score	15.72(6.57)	51.84(12.01)	48.89(10.94)

It is of note that four participants in the ASD group scored below the AQ clinical cut-off of 32/50. One participant in the OCD group scored above this cut-off with a score of 37/50 indicating a clinically significant level of autistic traits. With regards to EQ scores, one participant from the OCD group and one HC participant

scored below the cut-off of 30/80, with their scores of 28 and 23 respectively indicating deficits in empathy. One participant from the ASD group scored above this cut-off (32/80).

Significant effects of group on EQ and AQ scores were found,  $F(2, 33.28) = 100.27, p=.001, \omega^2=.71$  and  $F(2,54)=57.02, p<.001, \omega^2=.66$  respectively). Planned comparisons revealed that, as expected, EQ scores were significantly lower and AQ scores significantly higher in the ASD group,  $t(50.97)=14.30, p<.001, r=.89$  and  $t(54)= -10.55, p<.001, r=.82$  respectively. While EQ scores did not differ significantly between HC and OCD groups,  $t(35.69)=.791, p=.434, r=.13$ , AQ scores were significantly higher in the OCD compared to HC group,  $t(54)=1.80, p=.039, r=.24$ .

Bootstrapped, one-tailed Pearson's correlations were used to explore whether increased levels of autistic traits (as assessed by the EQ and AQ) were associated with higher OCD severity (as assessed by the Y-BOCS severity scale). Correlation coefficients and bootstrapped BCa 95% confidence intervals are displayed in Table 8.

Table 8.

*Bootstrapped one-tailed Pearson's correlations between AQ, EQ and Y-BOCS severity*

Measure of autistic traits	Y-BOCS severity score	
	<i>r</i> (54)	BCa 95% CI <sup>a</sup>
<b>EQ total score</b>	-.214 <sup>NS</sup>	[-.487, .073]
<b>AQ total score</b>	.402 <sup>***</sup>	[.142, .615]
<b>AQ subscales</b>		
Social skills	.360 <sup>**</sup>	[.096, .584]
Attention switching	.397 <sup>**</sup>	[.138, .612]
Attention to detail	.249 <sup>NS</sup>	[-.045, .521]
Communication	.304 <sup>*</sup>	[.050, .545]
Imagination	.377 <sup>**</sup>	[.151, .579]

<sup>a</sup> Based on 1000 bootstrap samples

\*  $p \leq .05$

\*\*  $p \leq .01$

\*\*\*  $p \leq .001$

<sup>NS</sup>  $p > 0.5$

Table 8 shows that AQ total score and social skills, attention switching, communication and imagination subscale scores are all significantly positively correlated with Y-BOCS severity scores, with *r* values ranging from .30 to .40, indicating medium effect sizes. No significant relationships were found between empathy or attention to detail and OCD severity ( $r = -.214$ , [-.487, .073],  $p = .06$  and  $r = .249$ , [-.045, .521],  $p = .067$ , respectively).



### Discussion

This study aimed to explore the obsessive-compulsive phenomena experienced by individuals with ASD and to consider these in comparison to the experiences of individuals with OCD and healthy controls.

Of the 18 participants with ASD, ten appeared to experience symptoms consistent with an OCD diagnosis, as identified using the MINI, and 12 reported the presence of obsessions and compulsions occupying over one hour daily and causing distress/impaired functioning when interviewed using the Y-BOCS. While this has potential implications for the study's findings, as discussed below, this also raises questions regarding the possibility of diagnostic-overshadowing and access to support. Despite all currently accessing mental health services or having done so in the recent past, only two of the twelve participants presenting with apparent OCD reported having accessed related interventions.

Unfortunately, lack of Y-BOCS symptom data for the majority of OCD participants meant comparisons between ASD and OCD groups could not be made. However, within the ASD group each category of common OCD obsessions and compulsions was endorsed by three or more participants. While Russell et al. (2005) found lower numbers of obsessions and compulsions in AS/HFA compared to OCD, the occurrence of these symptoms in comparison to healthy controls was not explored. In the current study the ASD group were found to experience significantly more obsessions and compulsions than healthy controls and in particular, contamination, sexual, hoarding, religious and symmetry obsessions and cleaning, checking and ordering compulsions were significantly more likely to occur in the ASD group.

Regarding current understandings of OCD and the theoretical link between obsessions and compulsions, it is of interest that of the 17 ASD participants reporting obsessive-compulsive symptoms, all reported experiencing both phenomena. This was in contrast to control group participants, 12 of whom reported experiencing both phenomena, while five reported obsessions only and two reported compulsions only. While such data were unavailable for the OCD group, Leonard and Rieman (2012) suggest individuals with OCD experience both, although sometimes this is only apparent with thorough exploration.

While McDougle et al. (1995) found individuals with ASD experienced more compulsions than obsessions, the opposite was found in the current study and that conducted by Russell et al. (2005), perhaps reflecting the differences in ASD samples. Over 50% of McDougle et al.'s sample had an LD and 30% were non-verbal. Therefore, parent/carer report was utilised when assessing symptom presence. In contrast the ASD samples in the current study and the study conducted by Russell et al. comprised of individuals with AS/HFA, all of whom had IQs above 70, and perhaps were more able to verbalise their non-observable experiences.

In contrast to existing research, the current study aimed to explore responses to obsessions. Cognitive-behavioural models suggest compulsions are performed in order to neutralise the anxiety/discomfort resulting from obsessions. While healthy controls most frequently reported not actively doing anything in response to unwanted/distressing thoughts, the response reported to be used most frequently in the ASD and OCD groups was to do something to neutralise the thought, consistent with the definition of compulsions. As expected, OCD participants reported passively letting thoughts come and go significantly less frequently than the other two groups. The ASD and OCD groups both sought reassurance from others more often than

controls, perhaps indicating an anxiety associated with these experiences. These findings suggest the repetitive acts displayed by some individuals with ASD may in some cases be an attempt to neutralise anxiety resulting from obsessions and so may lie towards the compulsive/anxiety-reducing rather than impulsive/pleasure-seeking end of the proposed OCS impulsivity-compulsivity dimension. Further research is however required in order to draw firm conclusions regarding this question.

Contrary to previous studies of adult populations (Cath et al., 2008; Russell et al., 2005), Y-BOCS severity score was not found to differ significantly between ASD and OCD groups, both of whom scored higher than controls. While the current study and that conducted by Russell et al. (2005) both examined apparently similar samples of individuals with AS/HFA, mean Y-BOCS severity was found to be higher for the ASD group in the current study (20.6 compared to 16.2). This discrepancy may be partly explained by other differences in the samples, with the ASD group in the current study being older (mean 38.8 years compared to 27.9 years) and having a higher mean IQ. While the mean full scale IQ of the ASD sample in the current study was 113.31, mean verbal and performance IQs in Russell et al.'s sample were 99.18 and 93.68 respectively.

As discussed, the Y-BOCS severity scale combines numerous factors which previous studies have not explored separately. In terms of time occupied by symptoms, 12 ASD participants reported obsessions and compulsions taking up more than one hour daily, consistent with OCD diagnostic criteria. Distress scores were also examined separately and the ASD group were found to have reported significantly more distress than controls, suggesting that apparent obsessive-compulsive symptoms in this population can be ego-dystonic and distressing rather

than sources of pleasure as previously proposed by some. However, further exploration of the emotions elicited by obsessive thoughts and comparisons with the OCD group found participants with OCD reported significantly stronger negative emotions resulting from obsessions than participants with ASD, with the exception of distress regarding the content of obsessions. The ASD and HC groups did not differ significantly on these factors with the exception of worry. The apparent discrepancy between the fact that the ASD participants report more distress than controls but not more sadness, shame, guilt or disapproval, suggests that further exploration of the nature of this distress is required.

In line with suggestions of a shared neurological basis of ASD and OCD (Stein, 2000), previous studies have suggested an association between ASD traits and OCD severity (Anholt et al.; 2010, Cath et al., 2008). A significant, moderate correlation between AQ assessed ASD traits and OCD severity was found in the current study. In contrast to previous studies, this association was found across the total sample including a control group, suggesting this association is not limited to those with clinically significant symptoms. Further exploration of individual domains assessed by the AQ found significant, moderate correlations between imagination, communication, social skills and attention switching difficulties and severity scores. The association between attention to detail and OCD severity was of weak-moderate strength and was non-significant.

Unlike previous studies, a broader range of autistic traits were explored and a second measure, the EQ, was used to assess a skill commonly impaired in individuals with ASD. In contrast to the association between OCD severity and AQ scores, the association with EQ scores was non-significant and of weak-moderate strength. Furthermore, while AQ scores were significantly higher in the OCD

compared to the HC group, EQ scores did not differ significantly between the two groups. The findings of the current study are therefore consistent with previous reports of elevated rates of autistic traits in OCD (Bejerot et al., 2001; LaSalle et al, 2004), but also suggest that not all areas of autistic traits are elevated in this population.

Overall, the findings of the current study appear to suggest a high incidence of obsessive-compulsive symptoms in high-functioning individuals with ASD. This finding may potentially have important implications for clinical practice. The obsessions and compulsions experienced by individuals with ASD appear to in some cases be distressing, time-consuming and impair functioning; findings which conflict with previous views of these experiences as being ego-systonic and sources of pleasure in this population. These findings therefore highlight the importance of assessing the distress and interference of apparent obsessive-compulsive behaviours in individuals with ASD. In addition to symptom severity, individuals with ASD were found to experience both obsessions and compulsions, with the latter potentially being an attempt to neutralise the distress caused by the former. This implies the symptoms displayed by individuals with ASD may fit with current theoretical understandings of OCD and may therefore be amenable to psychological interventions, such as CBT, which are based upon these understandings.

### **Methodological Considerations and Implications for Further Research**

When considering these findings, the methodological limitations and the exploratory nature of some aspects of the research must be borne in mind.

While bootstrap procedures were employed in order to meet parametric assumptions and increase the reliability and validity of analyses, the limited sample size must still be noted. Although significant results were found for the majority of

variables explored, the limited sample may have impacted on the non-significant findings for some analyses. Larger samples would allow analyses such as discriminant analysis to be conducted in order to identify the factors, including specific symptoms, emotions and responses, which best distinguish diagnostic groups.

Recruitment method must also be held in mind when considering whether samples are representative of wider populations. In particular, it is possible that of the individuals with ASD invited to participate, those who identified themselves as experiencing distressing or elevated rates of obsessive-compulsive symptoms may have been more likely to respond. This potential bias may be partly responsible for the high rates of apparent OCD presentations in this sample.

Furthermore, while all ASD participants had clinically confirmed ASD diagnoses, four scored below the AQ cut-off of 32 (with scores ranging from 25-31). The widening of recruitment also meant there was potential variation in the methods and tools used to make diagnoses.

A major limitation was the unavailable data for some OCD participants, meaning symptom comparisons could not be made between OCD and ASD groups. However, with regards to this particular research question comparisons were able to be made with controls, and the wealth of existing OCD research used to draw some tentative conclusions regarding how the experiences of individuals with ASD and OCD may compare.

A further limitation was the lack of validated measure designed to explore emotions and responses associated with obsessions, particularly one previously used within ASD populations. The CIQ was piloted with this population in the current study, however the results suggest some possible limitations associated with its use.

Firstly, it appears the negative emotions included may not have captured those underlying the distress reported by the ASD group. Secondly, a number of participants described responses in the 'other' category which fell into one of the existing categories, perhaps demonstrating a lack of understanding of these categories and subsequently meaning that responses may not have accurately reflected participants' experiences. Further exploration and development of this measure may therefore be indicated, perhaps by including examples of each category of response or using an interview rather than self-report format.

Finally, the limited range of diagnoses within the ASD population can be considered as both a strength and a limitation. While the relatively homogeneous nature of the ASD population in terms of specific diagnosis reduces any variability due to this factor, further investigation is required in order to explore whether similar results are obtained with samples of different sub-diagnoses. It would also be important to consider how the variables explored in this study can be best assessed in individual with learning disabilities who may be less able to verbalise their experiences.

### **Conclusion**

While the limitations of this study must be borne in mind, findings suggest high-functioning adults with ASD may experience significantly more obsessive-compulsive symptoms than healthy controls and at a level of severity comparable to individuals with OCD. Perhaps more importantly, these symptoms may in some cases present in a manner consistent with a diagnosis of OCD with obsessions and compulsions occurring together and occupying more than one hour a day. These symptoms appear to cause more distress in individuals with ASD compared to

controls, although less than in individuals with a diagnosis of OCD. Further exploration is however required to understand the exact nature of this distress.

While tentative, the results of the current study stress the importance of routine thorough assessment of apparent obsessive-compulsive symptoms and related distress or impairment of functioning in individuals with ASD, although further research is required to develop appropriate assessment tools. Furthermore, the distressing nature of these symptoms and their apparent fit with theoretical models of OCD suggest the obsessive and compulsive symptoms presented by this population may be amenable to psychological intervention.



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**Major Research Project**

**SECTION C**

**Critical appraisal**

Word Count: 2000

A thesis submitted in partial fulfilment of the requirements of  
Canterbury Christ Church University for the degree of Doctor of  
Clinical Psychology.

July 2013

## Contents

<b>What research skills have you learned and what research abilities have you developed from undertaking this project and what do you think you need to learn further? .....</b>	<b>3</b>
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**What research skills have you learned and what research abilities have you developed from undertaking this project and what do you think you need to learn further?**

Prior to commencing my MRP my experience was limited to completing smaller, independent projects or working in large research teams. This was my first experience of taking the lead on this scale of project and negotiating NHS ethics. Through undergoing this process I have gained experience and confidence in writing proposals and ethics applications and have increased awareness of the consideration and preparation required.

My skills in reviewing and synthesising large amounts of literature have also been furthered. My interest in and desire to fully understand the topic area often led to me becoming engrossed in bodies of work beyond the scope of my review and feeling overwhelmed. Completion of Section A helped to develop my ability to maintain direction and complete a focussed review while also holding the broader theoretical, clinical and research context in mind.

I soon became acutely aware of the need to balance the numerous demands of research and work on several aspects of the project simultaneously. My timetable underwent a swift revision when I realised recruitment would not represent a distinct phase, but would be an on-going and often unpredictable component of the work. Despite my efforts, recruitment often felt slow and I was frustrated by the inconsistent flow as well as the need to rely on others to make initial contact with participants. I learned to be flexible in altering my timetable and working on other components of the project during low-points in recruitment.

The role of researcher was one which initially felt uncomfortable. While I had procedures outlined for dealing with any potential risks or distress which arose, I also frequently felt drawn to discuss symptoms further and use my clinical skills to offer support/advice. I found sharing this dilemma with others experienced in clinical research helpful in considering my role. I was reminded that while I could use my clinical skills to respond sensitively to the information shared, the consent participants had given was to participate in research and not a therapeutic session. This tension between clinician and researcher was not one I had initially anticipated. As a clinical psychologist hoping to be involved in both research and clinical work throughout my career this is a tension which I may continue to experience and have to negotiate and one which would be helpful to consider in clinical or research supervision.

Completion of this project also challenged me to become familiar with statistical analyses I had not previously used. As some variables did not meet the assumptions for parametric statistics I looked into using the bootstrap technique (Wilcox, 2005). Through my own reading and discussions with a statistics consultant I feel that my knowledge in the theory behind different statistical tests and my confidence in considering and selecting those most appropriate for a given dataset and question have been furthered.

**If you were able to do this project again, what would you do differently and why?**

When considering recruitment I obtained figures for the number of individuals meeting my inclusion criteria accessing the services I planned to recruit from. As these figures were far in excess of required numbers, I hoped they would be sufficient, but also looked into voluntary sector groups as contingencies. However, I

failed to anticipate the low response rates I would encounter or the impact of the complex needs of the clinical population on their ability to attend scheduled appointments.

Furthermore, my ethical approval specified that first contact with participants would be made by clinic staff who had numerous competing demands. While recognising the rationale behind this restriction, I often felt frustrated at not being able to be more active in this process. I dedicated time to presenting information regarding my project to staff and also chose to be based within clinics on the majority of my study days in order to have a regular presence within teams and build relationships. An unforeseen relocation of one of the clinics and changes in service staff midway through my project resulted in further delays to my recruitment.

Soon after beginning, I broadened recruitment to voluntary sector organisations and offered to give presentations regarding my project. This decision involved some compromise. While participants recruited from within NHS clinics had their diagnoses conformed by multi-disciplinary teams using standardised assessment tools, I was often unable to access information regarding the diagnostic procedure for participants recruited from elsewhere. If repeating this process, I may have instead chosen to expand recruitment to other NHS trusts. However time limitations, the need to apply for R&D approval and the possibility of populations in other specialist clinics being over-researched led me not to pursue this option.

I attempted to reduce burden to participants by selecting to use the Mini International Neuropsychiatric Interview (MINI; Sheehan et al., 1998) rather than the longer, more time-consuming Structured Clinical Interview for DSM-IV (SCID; First, Spitzer, Gibbon & Williams, 1996), thus allowing me to obtain the information required while minimising the time commitment for participants. For the same

reason, I decided to use the National Adult Reading Test (NART; Nelson, 1982) rather than more recent equivalents as this measure was used routinely within one clinic.

My decision not to repeat measures led to difficulties towards the end of my project. I had been assured by senior clinicians that Y-BOCS data were routinely collected for all the participants I had recruited through a specialist OCD clinic as part of the clinic's own research and had been repeatedly informed that these data were available when I requested access to them. However, at a very late date, only one month before the submission deadline, I was made aware that unfortunately only total scores and no raw data were available for this population, meaning I was unable to complete some planned analysis. In discussion with senior clinicians/researchers, it was decided it would be unethical to re-contact participants to ask them to repeat this measure within such a short timescale.

While working in collaboration with other clinicians and researchers is an essential part of completing larger scale clinical research, I found this aspect of my project particularly frustrating especially after having been repeatedly assured that the data were available. While this unfortunate event was unavoidable, in future I would perhaps agree clear deadlines as to when I needed to have access to existing data in order to avoid any last minute difficulties.

My concerns regarding recruitment were partly due to the large numbers required. The unanticipated slow rate of recruitment sometimes made me regret my choice and wonder whether I had made things unduly difficult by ambitiously undertaking a large project. At these times, returning to my literature review or meeting with a participant who expressed interest in the topic and a belief in the value of such research rekindled my passion for the project and determination to

continue with this work. If able to start this process again, I feel that I would not choose to do a different project, but rather would have begun with more realistic expectations of the nature of this type of work and the possible setbacks I may encounter. I have come to realise that such obstacles should not prevent the undertaking of a piece of work, but rather that planning contingencies and being accepting of the setbacks which may be encountered are key. Furthermore, while working within clearly defined timescales is important for any piece of research, I feel the completion of this piece of work within a clinical doctorate, where any delay in completion would potentially have significant financial and personal consequences, influenced the decisions I made. I feel I may have dealt with the setbacks I experienced differently if completing this research in another context.

**Clinically, as a consequence of doing this study, would you do anything differently and why?**

Prior to this project, I had a strong interest in working within neurodevelopmental services and this is an area of work I hope to pursue post-qualification. In the course of my clinical work I have often been allocated cases or taken part in case-discussions of individuals with ASD who present with obsessive-compulsive symptoms. Such cases have often lead to debates within teams regarding the nature of symptoms; whether they are indicative of the impairments associated with ASD and not necessarily distressing or a target for intervention, or whether they may indicate the presence of OCD and thus warrant appropriate evidence-based interventions (NICE, 2005).

Through reviewing the literature I have increased awareness of factors which may be important to consider when developing formulations and action plans, most notably the ego-dystonic quality and distress associated with obsessive-compulsive

symptoms. I have also developed experience in administering the Yale-Brown Obsessive Compulsive Scale (Y-BOCS; Goodman et al., 1989) to assess symptom presence and severity. Through repeated administration of this measure, I feel I have developed an awareness of the types of follow-up questions which can help to clarify the nature of symptoms and their impact.

As a result of this work, I would also now always consider doing a thorough screen for other difficulties, perhaps using a measure such as the MINI or one of the few ASD-specific tools which I became aware of through my literature search. Such screens provide a helpful context under which to consider apparent obsessions and compulsions as often these may be better explained by the presence of other difficulties.

**If you were to undertake further research in this area what would that research project seek to answer and how would you go about doing it?**

This MRP was initially intended to form part of a larger, on-going project. It was planned that data from participants with OCD and ASD would be collected and submitted for the MRP and further data would later be collected from healthy controls before publication. The inclusion of a control group has been missing from the majority of other studies in this area and thus few conclusions have been able to be drawn regarding whether the obsessive-compulsive experiences and related distress in individuals with ASD differ significantly from healthy controls. The last minute difficulty accessing some existing data for OCD participants led me to decide to bring the collection of a control group forward, thus allowing me to still answer my research questions and strengthen the conclusions I was able to draw regarding the experiences of individuals with ASD in comparison to both individuals with OCD and



healthy controls. The extremely short time period which I had available to recruit and collect my control group however meant that my sample was limited both in size and also in ability to match to the ASD group both in terms of age and gender.

In addition to creating age and gender match groups, collection of a larger data set would also allow exploration of the reliability and validity of the Cognitive Intrusions Questionnaire (CIQ; Freeston, Ladouceur, Thibodeau, & Gagnon, 1991) for exploring appraisals of obsessive thoughts and related responses in individuals with ASD. While it is hypothesised that the distress/ego-dystonia associated with obsessions and compulsions, the appraisals of obsessions and the attempts to neutralize the anxiety triggered through compulsions are key differences between the experiences of individuals with ASD and OCD, there are a lack of measures available which look specifically at these factors. While the CIQ appears to tap into many of the variables of interest, this measure has yet to be validated.

Many participants shared extremely insightful and rich reflections on their experiences of obsessive-compulsive symptoms and the understandings they have reached regarding these. I wondered whether these data would be adequately captured by the measures used and felt a desire to be able to record and capture these descriptions. It would therefore be of interest to complete a series of more in-depth case-studies utilising both qualitative and quantitative methodologies to further explore the experiences of a sample of individuals with ASD who also present with obsessive-compulsive symptoms.

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**Major Research Project**

**SECTION D**

**Appendices of supporting material**

A thesis submitted in partial fulfilment of the requirements of  
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## Contents

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<b>Appendix E:</b>	DSM-IV criteria for OCD
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<b>Appendix G:</b>	Participant invitation letter
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<b>Appendix I:</b>	Participant advertisement (clinical groups)
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<b>Appendix N:</b>	Autism Spectrum Quotient (AQ)
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- Appendix P:** Cognitive Intrusions Questionnaire (CIQ)
- Appendix Q:** REC approval letter
- Appendix R:** R&D approval letter
- Appendix S:** Consent forms
- Appendix T:** ANOVAs and MANOVAs exploring effect of gender on AQ and EQ total scores, Y-BOCS severity score, negative emotions triggered by obsessions and responses to obsessions
- Appendix U:** Summary of 'other' responses to obsessions
- Appendix V:** Annual update to REC panel
- Appendix W:** Presentation guidelines for Sage publications (including 'Autism')

## Appendix A: Literature search methodology

A literature search was conducted in December 2012 on Psych info, the Cochrane database of systematic reviews and Medline, using the search terms shown in table 1. No start date was specified and papers were limited to those in the English language.

**Table 1**

*Summary of search terms and Boolean operators used.*

ASD related terms (combined with 'OR')	'AND'	OCD related terms (combined with 'OR')
Autis*		Obsessi*
Asperger*		Compulsi*
HFA		OCD
PDD		
Pervasive developmental disorder		
ASC		
ASD		

After removal of duplicates, 1437 results remained. Titles were scanned for relevance and abstracts/articles were read when relevance was initially unclear. Only empirical studies which directly discussed the presence of OCD or OCD symptoms in individuals with ASD were included, although additional papers were accessed and read for context.

Papers using the terms 'obsessive' and 'compulsive' not in relation to OCD were excluded, as were studies exploring medication for obsessive-compulsive behaviour or those exploring the neurobiological basis of the disorders.

A further study was found by searching reference sections of relevant papers. A total of 21 studies (including one previous meta-analysis) exploring comorbid OCD in ASD were found along with seven papers directly comparing obsessive-compulsive symptoms in OCD and ASD. These papers form the basis of the following review.

## Appendix B: Summary of studies exploring rates of comorbid OCD in ASD

Study	n	Diagnoses	Gender (% male)	Recruitment	Age in years (mean (range))	IQ (mean (range))	Measures	Respondent	OCD prevalence	Limitations/considerations
Amr et al. (2012)	60	Not reported	62%	Psychiatric outpatient clinics	(6-11)	FSIQ: (20-105)	Clinical interview based on DSM-IV; Semi structured Interview for Children and Adolescents (SCICA)	Parent and child	55%	No information available regarding medical or developmental history or comorbid genetic syndromes.
Bakken et al. (2010)	62	100% Autism	73%	Specialist Autism Clinic	23.9 (14-57)	52% mild/moderate LD, 48% severe/profound LD	Psychopathology in Autism Checklist (PAC)	Parent/carer	12.9%	Severe adjustment problems scores were required for diagnosis
Bradley et al. (2011)	36	Not reported	Not reported	Population-based sample	(14-20)	Non-verbal IQ<75	Schedule for the Assessment of Psychiatric Problems associated with Autism (SAPPA)	Parent/carer	0%	Ego-dystonic nature of experiences could not be ascertained so no diagnoses recorded.
De Bruin et al. (2007)	94	100% PDD-NOS	88.3%	Psychiatric outpatient clinics	8.5 (6-12)	FSIQ: 91.22 (55-120)	Diagnostic Interview Schedule for Children IV (DISC-IV)	Parent	6.4%	
Gadow et al. (2004)	182	37% Autism 13% AS 50% PDD-NOS	79%	Psychiatric outpatient clinics	4.2 (3-5)	FSIQ: 79	Early Child Inventory- 4 (ECI-4)	Parent and teacher	35.2%	Large sample of pre-school children Diagnoses determined using cut-offs on symptom rating scale - not based on DSM criteria.
Gillott et al. (2001)	15	100% HFA	87%	Psychiatric outpatient clinics	10.27 (8-12)	FSIQ>70	Spence Children's Anxiety Scale (SCAS)	Self-report	20%	Used subscale of a single self-report anxiety measure to assess OCD
Gjevik et al (2011)	71	66% Autism 17% AS 17% PDD-NOS	82%	Special educational needs schools	11.8 (6.2-17.9)	Non-verbal IQ: 65.2 (30-129)	KSADS	Parent	10%	
Green et al. (2000)	20	AS	100%	Psychiatric outpatient clinics	13.75 (11-19)	FSIQ: 92.15 (71-141)	Isle of Wight Semi-Structured Interview (IOW)	Parent	25%	Many participants had had inpatient admissions. Ego-dystonia and insight required for diagnosis.
Hutton et al. (2008)	135	Not reported	77%	Follow-up of individuals diagnosed with ASD in childhood	34.9 (21-57)	Non-verbal IQ (33-133)	Modified version of Child and Adolescent Psychiatric Assessment (CAPA)	Parent/carer	3.7%	Follow up study exploring emergence of new psychiatric disorders during adolescence/adulthood. 81.5% participation rate
Lai et al. (2011).	62	HFA or AS (numbers nor reported)	53%	Voluntary organisations	27 (18-45)	FSIQ>70 Mean: 113	Obsessive Compulsive Inventory- Revised (OCI-R)	Self-report	72.2% of males 69% of females	No significant differences in rates of comorbid OCD in males and females. OCI-R cut-off used to indicate diagnosis.
Leyfer et al. (2006)	109	Not reported	94.2%	Voluntary organisations	9.2 (5.1-17)	FSIQ: 82.55 (42-141) 67.71% had FSIQ>70	Autism Comorbidity Interview (ACI)	Parent	37.2%	90% inter-rater agreement for OCD diagnoses.



										Subjective mental experiences inferred from parent observations.
Mattila et al. (2010)	50	46% HFA 54% AS	76%	Community and specialist clinics	12.7 (9.8-16.3)	FSIQ>75	K-SADS	Child and parent	22% Community: 11% Clinic: 25%	Compared community and clinic samples. High attrition rate in community sample (125 screened and invited to participate, 18 completed measures)
Mazefsky et al. (2011)	38	Autism, PDD-NOS or AS (numbers not provided)	82%	Hospital clinic (fliers and "word of mouth")	12 (10-17)	FSIQ>70	Autism Comorbidity Interview (ACI)	Parent	2.6% (further 10.5% had sub-syndromal presentations)	Compared self- and parent report, but parent report used to determine diagnoses.
Mukkadde s et al. (2010a)	37	100% AS	86%	Psychiatry clinic	10.9 (6-20)	FSIQ 90-139	K-SADS	Child and parent	32%	
Mukkadde s et al. (2010b)	60	50% HFA 50% AS	100%	Psychiatry clinic	HFA: 10.3 (6.2-14.4) AS: 11.0 (7.0-15.5)	FSIQ HFA: 90.5 (70-127) AS: 106.5 (82-138)	K-SADS	Child and parent	36.7%	Comparison of HFA and AS groups matched for age and gender. No difference in rates of OCD between groups.
Muris et al. (1998)	44	34% Autism 66% PDD-NOS	Not reported	ASD clinic	9.7 (2-18) Autism: 5.9 PDD-NOS:	FSIQ: 79,5 (56-116) Autism: 70,5 PDD-NOS: 84.1	Diagnostic Interview Schedule for Children IV (DISC-IV)	Parent	11.4%	72.7% of children displayed obsessions/compulsions, but only 11.4% met diagnostic criteria as [parents were unsure as to whether these experiences caused distress.
Pertusa et al. (2012)	64	Not reported	58%	Specialist clinics and voluntary organisations	30.7	VIQ>70	Mini International Neuropsychiatric Interview (MINI)	Self-report	27.9%	Participants recruited to study looking specifically at hoarding.
Simonoff et al. (2008)	112	Not reported	Not reported	Population-derived sample	11.5 (10-14)	FSIQ: 72.7 (19-124)	Child and Adolescent Psychiatric Assessment (CAPA)	Parent	8.2%	
Witwer & Lecavalier (2010)	61	26% AS 28% Autism 43% PDD-NOS 3% not stated	82%	Psychiatric clinics and voluntary organisations	11.2 (6-17)	FSIQ: 68.4 (42-150)	Children's Interview for Psychiatric Symptoms – Parent version (P-ChIPS)	Parent	4.9%	Parents asked to infer child's thoughts to rate obsessions. Authors report difficulty distinguishing OCD symptoms from RRBs.
Wozniak et al. (1997)	66	100% PDD	64% Autism 36% PDD-NOS	Pediatric clinic	10	14% had LD	K-SADS	Parent	15.2%	Used non-hierarchical approach to daignosis

## Appendix C: Summary of studies comparing obsessions and compulsions in OCD and ASD

Study	N	ASD subtypes	Age (years)	Gender (% male)	IQ	Recruitment	Measures	Respondent	Comments
<b>Comparisons of ASD and OCD</b>									
Zandt et al. (2007)	54 (19 ASD, 17 OCD, 18 control)	15 AS, 3 Autistic disorder, 1PDD-NOS	Range: 7-16 Means: ASD=11 OCD=8 Controls= 12  No significant differences between groups	ASD: 84.2% OCD: 47.1% Controls: 33.3%	IQ>70  No significant differences between groups	Outpatient clinics, private psychologists/psyc hiatrists, newsletter advertisements. Controls recruited through schools.	Repetitive Behaviour Questionnaire (RBQ), CY-BOCS	Parent (children/adolescents joined parents for CY-BOCS interview for 68.4% of ASD group, 29.4% of OCD group and 11.1% of control group)	Diagnoses not based on use of standardised diagnostic tools. Lack of structured diagnostic interview to explore presence of comorbid disorders (including OCD). Groups not matched on gender. Diversity in ASD subtypes, but results did not differ when Autism and PDD-NOS removed.
Ruta et al. (2010)	60 (18 ASD, 20 OCD, 22 controls)	18 AS (confirmed using ADOS and ADI)	Range: 8-15 Means: ASD=10.61 OCD= 11.65 Controls= 10.68	ASD: 89% OCD: 80% Controls: 77%	FSIQ>70 Mean FSIQ: ASD: 91.89 OCD: 95.60 Controls: 95.68	ASD and OCD groups recruited through consecutive referrals to neuropsychiatry clinic. Controls recruited through schools.	K-SADS-PL (confirmation of OCD diagnosis and screening for other disorders) CY-BOCS	Children and parents	Used both self-report and parent report for CY-BOCS. ASD group all had same subtype (AS), confirmed with both ADOS and ADI. Screening interview used (K-SADS). None of the AS group reported to have comorbid OCD.
McDougle et al. (1995)	50 ASD, 50 OCD	50 Autistic disorder	Groups matched on age. Range: 18-53 Means: ASD=30.4 OCD=30.1	72%  Groups matched on gender.	Mean FSIQ: ASD: 69.7 OCD: not assessed, referral criteria = IQ>70  ASD group: 20% mild LD, 20% moderate LD, 16% profound LD. 30% non-verbal	Consecutive referrals to PDD clinic. Age and gender matched OCD group recruited from OCD clinic.	Y-BOCS	Parent/caregiver and participants for ASD group	DSM criteria for egodystonia and poor insight suspended Changed categories of Y-BOCS obsessions and compulsions – new categories created using items previously classed as miscellaneous. Significant differences in IQ between groups. One third of ASD group non-verbal and so unable to report on obsessions. Reliant on parent/caregiver reports.
Russell et al. (2010)	40 ASD, 45 OCD	36 AS, 4 HFA	Means: ASD=27.9 OCD=36.6	ASD: 85% OCD: 87%  Groups matched on gender.	FSIQ>70	ASD group recruited through consecutive referrals to an ASD clinic. Matched OCD group recruited form OCD clinic.	Y-BOCS	Self-report	OCD group significantly older than ASD group. Information regarding comorbid disorders not available for three ASD participants. 50% of ASD group had additional diagnoses 25% had comorbid OCD – analysis was repeated comparing OCD and OCD+ASD subgroup. Measures taken to ensure participants understood definitions of obsessions and compulsions so these phenomena were distinguished from RRBs etc.

									Miscellaneous obsessions and compulsions not included.
<b>Comparisons of OCD and comorbid ASD and OCD</b>									
Lewin et al. (2011)	35 OCD 35 OCD+ASD	17 Autism 9 AS 9 PDD-NOS	Range:7-13 Mean=9.9 , Groups matched on age	80% Groups gender matched	FSIQ>70	Pediatric clinics	Anxiety Disorders Interview Schedule for Parents and Children, 4 <sup>th</sup> Ed (ADIS-IV-C/P) CY-BOCS	Parent and child	Range of ASD diagnoses Recruited through clinic specialising in ASD and OCD. No 'pure' ASD comparison group Rates of comorbid disorders significantly higher in OCD+ASD group compared to pure OCD group.
Mack et al, 2010	12 OCD+ASD, 12 OCD		Range: 9-18 Mean: OCD+ASD: 14.33 OCD: 13.92	83.3% Groups gender matched	Only available for 5 OCD+ASD and 3 OCD Means: OCD+ASD: 99 OCD: 98	Specialist OCD clinic	CY-BOCS, Children's Obsessive Compulsive Inventory (CHOCI) SDQ	Children	Small sample size Lack of structured diagnostic interviews for ASD IQ only assessed in small proportion of participants Compulsions and autistic rituals distinguished through interview – had to be experienced as ego-dystonia, unwanted, distressing and preceded by a feeling of anxiety to be classed as a compulsion. groups matched for age and gender
Cath et al (2008)	12 OCD 6 OCD+ASD 12controls		Mean OCD=35.9 ASD=34.5 Controls=32.4	83% male Groups gender matched	All participants were educated to degree level.	Outpatient anxiety service	SCID Y-BOCS, AQ, 4 questions regarding ego-dystonia	Self-report	Small sample size Multiple comparisons – increased chance of type I error. Presence of ASD confirmed by two clinicians using DSM-IV criteria, but only 50% of ASD sample than scored above cut-of on AQ.

## Appendix D: Summary of results of studies comparing obsessions and compulsions in OCD and ASD

	Zandt et al. (2007)	Ruta et al. (2010)	McDougle et al. (1995) <sup>bc</sup>	Russell et al. (2005) <sup>b</sup>	Lewin et al. (2011) <sup>b</sup>	Mack et al. (2010)	Cath et al. (2008)
<b>OBSESSIONS</b>							
Aggressive	OCD>ASD <sup>a</sup>	<b>OCD&gt;ASD</b> ; ASD=C; OCD>C	<b>OCD&gt;ASD</b> , <i>OCD-1</i>	-	OCD=OCD+ASD	OCD=OCD+ASD	OCD=OCD+ASD
Contamination	OCD>ASD <sup>a</sup>	<b>OCD&gt;ASD</b> ; ASD=C; OCD>C	<i>ASD-3</i> , <i>OCD-2</i>	-	OCD=OCD+ASD	OCD=OCD+ASD	OCD=OCD+ASD>C
Hoarding/saving	OCD>ASD <sup>a</sup>	OCD<ASD <sup>NS</sup> ; ASD>C; OCD=C	<i>ASD-2</i>	-	-	OCD=OCD+ASD	OCD=OCD+ASD=C
Religious	OCD=ASD <sup>a</sup>	OCD=ASD=C	-	-	OCD=OCD+ASD	OCD=OCD+ASD	-
Sexual	OCD>ASD <sup>a</sup>	OCD=ASD=C	-	<b>OCD&gt;OCD+ASD</b>	<b>OCD&gt;OCD+ASD</b>	OCD=OCD+ASD	-
Symmetry/exactness	-	-	<b>OCD&gt;ASD</b> , <i>OCD-3</i>	-	-	-	OCD=OCD+ASD
Somatic	OCD>ASD <sup>a</sup>	OCD=ASD; ASD=C; OCD>C	-	<b>OCD&gt;ASD</b> ; <b>OCD&gt;OCD+ASD</b>	-	OCD>OCD+ASD <sup>NS</sup>	-
Superstitious	OCD>ASD <sup>a</sup>	OCD=ASD=C	-	-	-	OCD=OCD+ASD	-
Miscellaneous	OCD<ASD	-	-	-	-	-	-
Need to know/remember	-	-	<i>ASD-1</i>	-	-	-	-
Number of obsessions	<b>OCD&gt;ASD&gt;C</b>		<b>OCD&gt;ASD</b>	<b>OCD&gt;ASD</b>	-		-
<b>COMPULSIONS</b>							
Cleaning/washing	OCD>ASD <sup>a</sup>	OCD=ASD; ASD>C; OCD>C	<i>OCD-2</i>	-	<b>OCD&gt;OCD+ASD</b>	OCD=OCD+ASD	OCD=OCD+ASD>C
Checking	OCD>ASD <sup>a</sup>	<b>OCD&gt;ASD</b> ; ASD=C; OCD>C	<b>OCD&gt;ASD</b> , <i>OCD-1</i>	<b>OCD&gt;ASD</b>	<b>OCD&gt;OCD+ASD</b>	OCD=OCD+ASD	OCD=OCD+ASD
Repeating	OCD>ASD <sup>a</sup>	OCD=ASD; ASD>C; OCD>C	<i>OCD-3</i>	<b>OCD&gt;ASD</b>	<b>OCD&gt;OCD+ASD</b>	OCD=OCD+ASD	-
Counting	OCD>ASD <sup>a</sup>	OCD=ASD=C	<b>OCD&gt;ASD</b>	-	OCD=OCD+ASD	OCD=OCD+ASD	-
Ordering/arranging	OCD=ASD <sup>a</sup>	OCD<ASD <sup>NS</sup> ; ASD>C; OCD>C	<i>ASD-2</i>	-	OCD=OCD+ASD	OCD=OCD+ASD	OCD=OCD+ASD
Hoarding/collecting	OCD>ASD <sup>a</sup>	OCD<ASD <sup>NS</sup> ; ASD>C; OCD=C	<b>OCD&lt;ASD</b> , <i>ASD-3</i>	-	OCD=OCD+ASD	OCD=OCD+ASD	OCD=OCD+ASD=C
Miscellaneous	OCD>ASD <sup>a</sup>	-	-	-	-	-	-
Superstitious/magical	OCD>ASD <sup>a</sup>	OCD=ASD=C	-	-	-	OCD>OCD+ASD <sup>NS</sup>	-
Other person	OCD=ASD <sup>a</sup>	OCD=ASD; ASD=C; OCD>C	-	-	-	OCD=OCD+ASD	-
Need to touch/tap/rub	-	-	<b>OCD&lt;ASD</b> , <i>ASD-1</i>	-	OCD=OCD+ASD	-	-
Self-damaging	-	-	<b>OCD&lt;ASD</b>	-	-	-	-
Asking or confessing	-	-	-	-	OCD=OCD+ASD	-	-
Mental rituals	-	-	-	-	OCD=OCD+ASD	-	-
Number of compulsions	<b>OCD&gt;ASD&gt;C</b>		OCD=ASD	<b>OCD&gt;ASD</b>	-		-
<b>SEVERITY</b>							
Obsessions severity				<b>OCD&gt;ASD</b>	OCD=OCD+ASD	OCD=OCD+ASD	<b>OCD&gt;OCD+ASD&gt;C</b>
Compulsions severity				<b>OCD&gt;ASD</b>	OCD=OCD+ASD	OCD=OCD+ASD	OCD=OCD+ASD>C
TOTAL SEVERITY	<b>OCD&gt;ASD&gt;C</b>			<b>OCD&gt;ASD</b>	OCD=OCD+ASD	OCD=OCD+ASD	<b>OCD&gt;OCD+ASD&gt;C</b>

<sup>a</sup> Authors state that OCD group more likely than ASD group to report most types of obsessions and compulsion but no indication of whether or not this difference is significant for each category.

<sup>b</sup> Analysis took the form of discriminant function analysis. Obsessions and compulsions found to best predict group membership and the direction of difference shown in bold and underlined.

<sup>c</sup> The three most common obsessions and compulsions endorsed by each group are signified by the group name and number (indicating, 1<sup>st</sup>, 2<sup>nd</sup> and 3<sup>rd</sup> most common)

## Appendix E: DSM-IV criteria for OCD

### **Diagnostic criteria for 300.3 Obsessive-Compulsive Disorder**

A. Either obsessions or compulsions:

*Obsessions as defined by (1), (2), (3), and (4):*

(1) recurrent and persistent thoughts, impulses, or images that are experienced at some time during the disturbance, as intrusive and inappropriate and that cause marked anxiety or distress

(2) the thoughts, impulses, or images are not simply excessive worries about real-life problems

(3) the person attempts to ignore or suppress such thoughts, impulses, or images, or to neutralize them with some other thought or action

(4) the person recognizes that the obsessional thoughts, impulses, or images are a product of his or her own mind (not imposed from without as in thought insertion)

*Compulsions as defined by (1) and (2):*

(1) repetitive behaviors (e.g., hand washing, ordering, checking) or mental acts (e.g., praying, counting, repeating words silently) that the person feels driven to perform in response to an obsession, or according to rules that must be applied rigidly

(2) the behaviors or mental acts are aimed at preventing or reducing distress or preventing some dreaded event or situation; however, these behaviors or mental acts either are not connected in a realistic way with what they are designed to neutralize or prevent or are clearly excessive

B. At some point during the course of the disorder, the person has recognized that the obsessions or compulsions are excessive or unreasonable. Note: This does not apply to children.

C. The obsessions or compulsions cause marked distress, are time consuming (take more than 1 hour a day), or significantly interfere with the person's normal routine, occupational (or academic) functioning, or usual social activities or relationships.

D. If another Axis I disorder is present, the content of the obsessions or compulsions is not restricted to it (e.g., preoccupation with food in the presence of an Eating Disorder; hair pulling in the presence of Trichotillomania; concern with appearance in the presence of Body Dysmorphic Disorder; preoccupation with drugs in the presence of a Substance Use Disorder; preoccupation with having a serious illness in the presence of Hypochondriasis; preoccupation with sexual urges or fantasies in

the presence of a Paraphilia; or guilty ruminations in the presence of Major Depressive Disorder).

E. The disturbance is not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition.

Specify if:

With poor insight: if, for most of the time during the current episode, the person does not recognise that the obsessions and compulsions are excessive or unreasonable.

## Appendix F: ICD-10 criteria for OCD

### F42 Obsessive-Compulsive Disorder

The essential feature of this disorder is recurrent obsessional thoughts or compulsive acts. (For brevity, "obsessional" will be used subsequently in place of "obsessive-compulsive" when referring to symptoms.) Obsessional thoughts are ideas, images or impulses that enter the individual's mind again and again in a stereotyped form. They are almost invariably distressing (because they are violent or obscene, or simply because they are perceived as senseless) and the sufferer often tries, unsuccessfully, to resist them. They are, however, recognized as the individual's own thoughts, even though they are involuntary and often repugnant. Compulsive acts or rituals are stereotyped behaviours that are repeated again and again. They are not inherently enjoyable, nor do they result in the completion of inherently useful tasks. The individual often views them as preventing some objectively unlikely event, often involving harm to or caused by himself or herself. Usually, though not invariably, this behaviour is recognized by the individual as pointless or ineffectual and repeated attempts are made to resist it; in very long-standing cases, resistance may be minimal. Autonomic anxiety symptoms are often present, but distressing feelings of internal or psychic tension without obvious autonomic arousal are also common. There is a close relationship between obsessional symptoms, particularly obsessional thoughts, and depression. Individuals with obsessive-compulsive disorder often have depressive symptoms, and patients suffering from recurrent depressive disorder may develop obsessional thoughts during their episodes of depression. In either situation, increases or decreases in the severity of the depressive symptoms are generally accompanied by parallel changes in the severity of the obsessional symptoms.

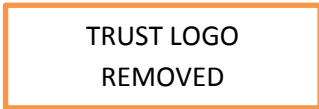
Obsessive-compulsive disorder is equally common in men and women, and there are often prominent anankastic features in the underlying personality. Onset is usually in childhood or early adult life. The course is variable and more likely to be chronic in the absence of significant depressive symptoms.

#### Diagnostic Guidelines:

For a definite diagnosis, obsessional symptoms or compulsive acts, or both, must be present on most days for at least 2 successive weeks and be a source of distress or interference with activities. The obsessional symptoms should have the following characteristics:

- (a) they must be recognized as the individual's own thoughts or impulses:
- (b) there must be at least one thought or act that is still resisted unsuccessfully, even though others may be present which the sufferer no longer resists;
- (c) the thought of carrying out the act must not in itself be pleasurable (simple relief of tension or anxiety is not regarded as pleasure in this sense);
- (d) the thoughts, images, or impulses must be unpleasantly repetitive

## Appendix G: Participant invitation letter



### **Obsessions and compulsions in OCD and ASD**

You are being invited to take part in a research study. You are being invited because we understand that you may fulfil the criteria for the study and that you may be interested in taking part.

Please take some time to carefully read the information sheet that accompanies this letter. Talk to others about the study if you wish, and please feel free to contact me if you have any questions. I would be happy to discuss the study with you and provide any additional information.

I hope that if you do choose to participate you will find it an interesting experience. In addition, I hope that the results of the study will help contribute to the understanding of experiences of obsessions and compulsions, which may ultimately lead to enhanced clinical care.

Yours faithfully

**Cathy Saddington**

Trainee Clinical Psychologist

Canterbury Christ Church University





## Appendix H: Participant information sheets

OCD & ASD

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### PARTICIPANT INFORMATION SHEET

#### Obsessions and compulsions in OCD and ASD

My name is Cathy Saddington and I am a trainee clinical psychologist working for the NHS. As part of my clinical doctorate I am completing some research, supervised by Dr Neil Harrison and Dr Daniel Salter.

You are being invited to participate in the research, but before you decide whether you would like to take part please read and consider the following information.

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

Many people experience persistent thoughts or images which they find intrusive or inappropriate and/or repetitive behaviours (including mental acts) which they feel compelled to carry out. These experiences are sometimes referred to as 'obsessions' and 'compulsions'. For some people, obsessions and compulsions may cause them a great deal of distress and disrupt their lives, leading them to seek help from a professional. These people may receive a diagnosis of Obsessive Compulsive Disorder (OCD). People with other disorders such as Body Dysmorphic Disorder, an Autistic Spectrum Disorder or Tourettes, and other members of the general population may also experience obsessions and compulsions at some point in their life. These experiences can vary greatly in their frequency and the amount of distress and disruption they cause the individual experiencing them.

The study you are being asked to take part in aims to further our understanding of these experiences and how they may vary between different people. It will also look at people's thoughts about these experiences and whether the presence of obsessions and compulsions is linked to other aspects of people's feelings and behaviour.

### **Why am I being asked to take part?**

This study is particularly interested in the experiences of people who have a diagnosis of obsessive compulsive disorder (OCD) or an autistic spectrum disorder (ASD). You have been invited to take part as you fit the criteria for the study.

### **What will taking part involve?**

If you decide to take part in the study, an appointment will be made for you to meet with the researcher at an NHS clinic for approximately two hours. You will be asked some questions by the researcher during an interview. These questions will ask you about any difficulties you may be experiencing (such as anxiety) and about any experiences of obsessions or compulsions you have had. You will also be asked to complete a short reading task which takes approximately 5 minutes and is used to provide a rough indicator of how your brain works.

As well as meeting with the researcher, you will also be asked to complete some short questionnaires which take approximately 20 minutes to complete. The questionnaires will ask about your feelings and behaviour and you will be asked to circle the responses which relate to you.

### **What are the benefits of taking part?**

Taking part in this research may help to increase our understanding of people's experiences of obsessions and compulsions.

Your contribution and time would be greatly appreciated.

As a token of appreciation for your participation you will receive £15. Your travel costs to the clinic will also be reimbursed.

### **What should I do if I have any concerns about how the research is conducted?**

If you have any concerns or complaints regarding this research, you would be encouraged to contact the lead researcher, named below, in the first instance. If your complaint could not be addressed to your satisfaction and you want to make a formal complaint you can do so by contacting Paul Camic, Professor of Psychology & Research Director at:

Department of Applied Psychology  
Canterbury Christ Church University  
Broomhill Road

Tunbridge Wells, Kent TN3 0TG.  
Tel: 01892 507 773

You can also obtain advice from the Patient Advice and Liaison Service (PALS):

[REDACTED]

PALS

[REDACTED]

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

While your participation would be very much appreciated, you are not obliged to take part in this research. Your decision of whether or not to take part will not have any impact on the care you are already receiving through the clinic.

If you do decide to take part in the study, you are still free to withdraw your participation at any point without having to provide a reason for doing so and any data you have provided will be withdrawn.

### **What will happen to the information I provide?**

The information you provide while participating in this study will be confidential. However, if during your participation you share information with the researcher which makes them concerned about your safety or the safety of another individual, then they have a duty to share this information with the relevant professionals, such as your GP or care-coordinator. If you report any other symptoms during your participation, the researcher will advise you as to how to access support if you wish to do so. The researcher can also contact your GP or care-coordinator on your behalf if you would like them to do so.

The questionnaires you complete will be stored in a secure location and destroyed following completion of the research. Data gathered during the research will be entered into a computer program. This data will be anonymous which means that it will not include your name or any other information which could be used to identify you.

The results of the research will be written up and submitted to Canterbury Christchurch University as part of the clinical psychology training programme and may also be submitted to a journal for publication. Again these reports will not include identifiable information about any of the participants. If you would like to receive a short summary of the overall results of the whole study, this will be available after July 2013 and can be obtained by contacting the researcher on the details provided below.

### **Has this research been approved?**

This study has been approved by Canterbury Christchurch University and has also been reviewed by the National Research Ethics Service (NRES) committee of the South East Coast, Brighton and Sussex.

If you have any further questions regarding this research please contact Cathy Saddington, Trainee Clinical Psychologist, on 07930 866 676. If you leave a message your call will be returned as soon as possible. If for any reason you feel upset or distressed as a result of your participation, please use the contact details above and you will be provided with details of where you may obtain further help.

**Thank you for taking the time to read this information.**

**Cathy Saddington,**

**Trainee Clinical Psychologist**

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## **PARTICIPANT INFORMATION SHEET**

### **Obsessions and compulsions in OCD and ASD**

My name is Cathy Saddington and I am a trainee clinical psychologist working for the NHS. As part of my clinical doctorate I am completing some research, supervised by Dr Neil Harrison and Dr Daniel Salter.

You are being invited to participate in the research, but before you decide whether you would like to take part please read and consider the following information.

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

Many people experience persistent thoughts or images which they find intrusive or inappropriate and/or repetitive behaviours (including mental acts) which they feel compelled to carry out. These experiences are sometimes referred to as 'obsessions' and 'compulsions'. For some people, obsessions and compulsions may cause them a great deal of distress and disrupt their lives, leading them to seek help from a professional. These people may receive a diagnosis of Obsessive Compulsive Disorder (OCD). People with other disorders such as Body Dysmorphic Disorder, an Autistic Spectrum Disorder or Tourettes, and other members of the general population may also experience obsessions and compulsions at some point in their life. These experiences can vary greatly in their frequency and the amount of distress and disruption they cause the individual experiencing them.

The study you are being asked to take part in aims to further our understanding of these experiences and how they may vary between different people. It will also look at people's thoughts about these experiences and whether the presence of obsessions and compulsions is linked to other aspects of people's feelings and behaviour.

### **Why am I being asked to take part?**

This study is particularly interested in the experiences of people who have a diagnosis of obsessive compulsive disorder (OCD) or an autistic spectrum disorder (ASD). However, in order to better understand the experiences of these two groups and how they differ from the experiences of the general population, we want to compare them to a control group consisting of members of the population who do not have a diagnosis of OCD or ASD.

### **What will taking part involve?**

If you decide to take part in the study, the researcher will contact you to arrange a time to meet for approximately 1 ½ hours. This meeting can be conducted in your home or on Canterbury Christ Church University premises. You will be asked some questions by the researcher during an interview. These questions will ask you about any difficulties you may be experiencing (such as anxiety) and about any experiences of obsessions or compulsions you have had. You will also be asked to complete a short reading task which takes approximately 5 minutes and is used to provide a rough indicator of how your brain works.

As well as meeting with the researcher, you will also be asked to complete some short questionnaires which take approximately 20 minutes to complete. The questionnaires will ask about your feelings and behaviour and you will be asked to circle the responses which relate to you.

### **What are the benefits of taking part?**

Taking part in this research may help to increase our understanding of people's experiences of obsessions and compulsions.

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If you have any concerns or complaints regarding this research, you would be encouraged to contact to the lead researcher, named below, in the first instance. If your complaint could not be addressed to your satisfaction and you want to make a

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Broomhill Road  
Tunbridge Wells, Kent TN3 0TG.  
Tel: 01892 507 773

You can also obtain advice from the Patient Advice and Liaison Service (PALS):

[REDACTED]

PALS

[REDACTED]

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

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### **What will happen to the information I provide?**

The information you provide while participating in this study will be confidential. However, if during your participation you share information with the researcher which makes them concerned about your safety or the safety of another individual, then they have a duty to share this information with the relevant professionals, such as your GP or care-coordinator. If you report any other symptoms during your participation, the researcher will advise you as to how to access support if you wish to do so. The researcher can also contact your GP or care-coordinator on your behalf if you would like them to do so.

The questionnaires you complete will be stored in a secure location and destroyed following completion of the research. Data gathered during the research will be entered into a computer program. This data will be anonymous which means that it will not include your name or any other information which could be used to identify you.

The results of the research will be written up and submitted to Canterbury Christchurch University as part of the clinical psychology training programme and may also be submitted to a journal for publication. Again these reports will not include identifiable information about any of the participants. If you would like to receive a short summary of the overall results of the whole study, this will be available after July 2013 and can be obtained by contacting the researcher on the details provided below.

### **Has this research been approved?**

This study has been approved by Canterbury Christchurch University and has also been reviewed by the National Research Ethics Service (NRES) committee of the South East Coast, Brighton and Sussex.

If you have any further questions regarding this research please contact Cathy Saddington, Trainee Clinical Psychologist, on 01892 507 694. If you leave a message your call will be returned as soon as possible. If for any reason you feel upset or distressed as a result of your participation, please use the contact details above and you will be provided with details of where you may obtain further help.

**Thank you for taking the time to read this information.**

**Cathy Saddington,**

**Trainee Clinical Psychologist**

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## Appendix I: Participant advertisement (clinical groups)



### Advertisement for participant recruitment

## Want to take part in a psychology research project?

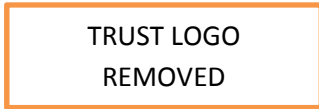
My name is Cathy Saddington and I am a trainee clinical psychologist working for the NHS. As part of my training I am completing some research which aims to compare the experiences of obsessions (persistent thoughts or images which people find intrusive or inappropriate) and compulsions (repetitive behaviours which people feel compelled to carry out) in individuals who have a diagnosis of Obsessive Compulsive Disorder (OCD) or an Autistic Spectrum Disorder (ASD).

We are looking for people aged 18-65 years who have a diagnosis of OCD or ASD to help with this research. Participation will involve answering a series of questions on questionnaires or through interviews with the researcher. This process will take approximately 2 hours and can be completed in a local NHS clinic. You will be paid £15 for your time if you choose to participate and your travel costs to the clinic will also be reimbursed.

If you would like to find out more about this project or are interested in taking part please contact **Cathy Saddington**:



## Appendix J: Participant advertisement (control group)



### Advertisement for participant recruitment

## Want to take part in a psychology research project?

My name is Cathy Saddington and I am a trainee clinical psychologist working for the NHS. As part of my training I am completing some research which aims to compare the experiences of obsessions (persistent thoughts or images which people find intrusive or inappropriate) and compulsions (repetitive behaviours which people feel compelled to carry out) in individuals who have a diagnosis of Obsessive Compulsive Disorder (OCD) or an Autistic Spectrum Disorder (ASD).

This study is particularly interested in the experiences of people who have a diagnosis of obsessive compulsive disorder (OCD) or an autistic spectrum disorder (ASD). However, in order to better understand the experiences of these two groups and how they differ from the experiences of the general population, we want to compare them to a control group consisting of members of the population who do not have a diagnosis of OCD or ASD.

We are therefore looking for people aged 18-65 years who do not have a diagnosis of ASD or OCD to help with this research. Participation will involve answering a series of questions on questionnaires or through interviews with the researcher. This process will take approximately 1 ½ hours. You will be paid £15 for your time if you choose to participate.

If you would like to find out more about this project or are interested in taking part please contact **Cathy Saddington**:



## **Appendix K: Mini International Neuropsychiatric Interview (MINI)**

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## **Appendix L: National Adult Reading Test (NART)**

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## **Appendix M: Yale-Brown Obsessive Compulsive Scale (Y-BOCS)**

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## **Appendix N: Autism Spectrum Quotient (AQ)**

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## **Appendix O: Empathy Quotient (EQ)**

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## **Appendix P: Cognitive Intrusions Questionnaire (CIQ)**

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## **Appendix Q: REC approval letter**

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## **Appendix R: R&D approval letter**

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## Appendix S: Consent forms

OCD & ASD



### CONSENT FORM

**Title of project:** Obsessions and compulsions in OCD and ASD

**Name of researcher:** Cathy Saddington

Please read each of the following statement and initial the corresponding boxes:

- I confirm that I have read the information sheet relating to the study named above and have had the opportunity to ask questions.
- I am aware that my participation is voluntary and that I am free to withdraw from the study at any time without providing a reason and without any consequences for my continuing care.
- I understand that the information I provide will be stored securely and that data will be made anonymous.
- If I have completed any questionnaires/interviews used in this study as part of my ongoing care at the clinic I give my permission for clinic staff to share these with the researcher named above so as not to repeat their completion.
- While the information I provide will be treated as confidential, I am aware that if I disclose any information which may indicate a risk to my safety or the safety of another individual, this information may need to be shared with relevant professionals including my GP
- I understand that the research data collected during the study may be looked at by individuals from the sponsor organisation, from regulatory authorities and from the NHS Trust where it is relevant to my taking part in the study. I give permission for these individuals to have access to my records.
- I agree to take part in the study named above

**Name of participant:** \_\_\_\_\_

**Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

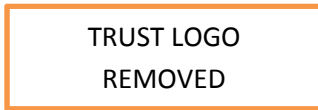
If you would like to receive a short summary of the overall results of the whole study, available after July 2013, please provide an email or postal address below:

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## CONSENT FORM

**Title of project:** Obsessions and compulsions in OCD and ASD

**Name of researcher:** Cathy Saddington

Please read each of the following statement and initial the corresponding boxes:

- I confirm that I have read the information sheet relating to the study named above and have had the opportunity to ask questions.
  - I am aware that my participation is voluntary and that I am free to withdraw from the study at any time without providing a reason and without any consequences for my continuing care.
  - I understand that the information I provide will be stored securely and that data will be made anonymous.
  - While the information I provide will be treated as confidential, I am aware that if I disclose any information which may indicate a risk to my safety or the safety of another individual, this information may need to be shared with relevant professionals, including my GP.
  - I understand that the research data collected during the study may be looked at by individuals from the sponsor organisation, from regulatory authorities and from the NHS Trust where it is relevant to my taking part in the study. I give permission for these individuals to have access to my records.
  - I agree to take part in the study named above
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**Name of participant:** \_\_\_\_\_

**Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

If you would like to receive a short summary of the overall results of the whole study, available after July 2013, please provide an email or postal address below:

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**Appendix T: ANOVAs and MANOVAs exploring effect of gender on AQ and EQ total scores, Y-BOCS severity score, negative emotions triggered by obsessions and responses to obsessions**

**Tests of Between-Subjects Effects**

Dependent Variable: AQ\_TOTAL

Source	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared
Corrected Model	6214.985 <sup>a</sup>	5	1242.997	24.700	.000	.708
Intercept	24334.024	1	24334.024	483.547	.000	.905
PRIMARY_DIAGNOSIS	3945.190	2	1972.595	39.198	.000	.606
gender	62.580	1	62.580	1.244	.270	.024
PRIMARY_DIAGNOSIS * gender	131.009	2	65.505	1.302	.281	.049
Error	2566.524	51	50.324			
Total	38203.000	57				
Corrected Total	8781.509	56				

a. R Squared = .708 (Adjusted R Squared = .679)

**Tests of Between-Subjects Effects**

Dependent Variable: EQ\_TOTAL

Source	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared
Corrected Model	15748.692 <sup>a</sup>	5	3149.738	35.159	.000	.779
Intercept	61474.631	1	61474.631	686.209	.000	.932
PRIMARY_DIAGNOSIS	9908.664	2	4954.332	55.303	.000	.689
gender	323.465	1	323.465	3.611	.063	.067
PRIMARY_DIAGNOSIS * gender	404.050	2	202.025	2.255	.115	.083
Error	4479.290	50	89.586			
Total	106421.000	56				
Corrected Total	20227.982	55				

a. R Squared = .779 (Adjusted R Squared = .756)

**Tests of Between-Subjects Effects**

Dependent Variable: YBOCS\_TOTAL\_SEVERITY

Source	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared
Corrected Model	3784.423 <sup>a</sup>	5	756.885	20.416	.000	.676
Intercept	11167.930	1	11167.930	301.245	.000	.860
PRIMARY_DIAGNOSIS	3531.730	2	1765.865	47.633	.000	.660
gender	39.261	1	39.261	1.059	.308	.021
PRIMARY_DIAGNOSIS * gender	58.431	2	29.216	.788	.460	.031
Error	1816.559	49	37.073			
Total	20361.000	55				
Corrected Total	5600.982	54				

a. R Squared = .676 (Adjusted R Squared = .643)

#### Tests of Between-Subjects Effects

Source	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared
Corrected Model	CIQ2.2_sad	80.452 <sup>a</sup>	5	16.090	3.168	.014	.237
	CIQ2.3_worried	91.632 <sup>b</sup>	5	18.326	4.644	.001	.313
	CIQ2.5_guilty	102.645 <sup>c</sup>	5	20.529	3.725	.006	.268
	CIQ2.7_disapprove	113.947 <sup>d</sup>	5	22.789	4.791	.001	.320
	CIQ2.15_ashamed	117.521 <sup>e</sup>	5	23.504	3.411	.010	.251
	CIQ2.21_content_disturbs	68.666 <sup>f</sup>	5	13.733	2.265	.062	.182
	CIQ2.22_presence_disturbs	102.611 <sup>g</sup>	5	20.522	3.906	.004	.277
	CIQ2.2_sad	1151.407	1	1151.407	226.675	.000	.816
	CIQ2.3_worried	1542.816	1	1542.816	390.984	.000	.885
Intercept	CIQ2.5_guilty	710.379	1	710.379	128.896	.000	.717
	CIQ2.7_disapprove	1172.838	1	1172.838	246.543	.000	.829
	CIQ2.15_ashamed	737.584	1	737.584	107.029	.000	.677
	CIQ2.21_content_disturbs	1161.741	1	1161.741	191.602	.000	.790
	CIQ2.22_presence_disturbs	1049.761	1	1049.761	199.805	.000	.797
	CIQ2.2_sad	1.674	1	1.674	.330	.568	.006
	CIQ2.3_worried	.266	1	.266	.067	.796	.001
	CIQ2.5_guilty	2.629	1	2.629	.477	.493	.009
	gender	CIQ2.7_disapprove	.530	1	.530	.111	.740
CIQ2.15_ashamed		7.652	1	7.652	1.110	.297	.021
CIQ2.21_content_disturbs		1.012	1	1.012	.167	.685	.003
CIQ2.22_presence_disturbs		.323	1	.323	.061	.805	.001
CIQ2.2_sad		79.948	2	39.974	7.870	.001	.236
PRIMARY_DIAGNOSIS	CIQ2.3_worried	90.271	2	45.135	11.438	.000	.310
	CIQ2.5_guilty	79.723	2	39.861	7.233	.002	.221



	CIQ2.7_disapprove	98.062	2	49.031	10.307	.000	.288
	CIQ2.15_ashamed	102.715	2	51.358	7.452	.001	.226
	CIQ2.21_content_disturbs	58.637	2	29.318	4.835	.012	.159
	CIQ2.22_presence_disturbs	101.807	2	50.904	9.689	.000	.275
	CIQ2.2_sad	8.017	2	4.008	.789	.460	.030
	CIQ2.3_worried	5.403	2	2.701	.685	.509	.026
	CIQ2.5_guilty	9.958	2	4.979	.903	.412	.034
gender *	CIQ2.7_disapprove	.501	2	.251	.053	.949	.002
PRIMARY_DIAGNOSIS	CIQ2.15_ashamed	1.767	2	.884	.128	.880	.005
	CIQ2.21_content_disturbs	11.838	2	5.919	.976	.384	.037
	CIQ2.22_presence_disturbs	6.091	2	3.045	.580	.564	.022
	CIQ2.2_sad	259.057	51	5.080			
	CIQ2.3_worried	201.245	51	3.946			
	CIQ2.5_guilty	281.074	51	5.511			
Error	CIQ2.7_disapprove	242.614	51	4.757			
	CIQ2.15_ashamed	351.462	51	6.891			
	CIQ2.21_content_disturbs	309.229	51	6.063			
	CIQ2.22_presence_disturbs	267.950	51	5.254			
	CIQ2.2_sad	1993.000	57				
	CIQ2.3_worried	2442.000	57				
	CIQ2.5_guilty	1328.000	57				
Total	CIQ2.7_disapprove	1925.000	57				
	CIQ2.15_ashamed	1389.000	57				
	CIQ2.21_content_disturbs	2053.000	57				
	CIQ2.22_presence_disturbs	1846.000	57				
	CIQ2.2_sad	339.509	56				
	CIQ2.3_worried	292.877	56				
	CIQ2.5_guilty	383.719	56				
Corrected Total	CIQ2.7_disapprove	356.561	56				
	CIQ2.15_ashamed	468.982	56				
	CIQ2.21_content_disturbs	377.895	56				
	CIQ2.22_presence_disturbs	370.561	56				

#### Tests of Between-Subjects Effects

Source	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	CIQ2.11a_goes_on_own_accord	59.901 <sup>a</sup>	5	11.980	2.023	.091
	CIQ2.11b_reassure_self	10.084 <sup>b</sup>	5	2.017	.339	.887

	CIQ2.11c_seek_reassurance	61.352 <sup>c</sup>	5	12.270	2.254	.063
	CIQ2.11d_neutralize	31.907 <sup>d</sup>	5	6.381	.809	.548
	CIQ2.11e_think_it_through	27.520 <sup>e</sup>	5	5.504	1.099	.372
	CIQ2.11f_replace_thought	45.025 <sup>f</sup>	5	9.005	1.701	.151
	CIQ2.11g_distract	6.069 <sup>g</sup>	5	1.214	.298	.912
	CIQ2.11h_absorbing_activity	37.405 <sup>h</sup>	5	7.481	1.919	.107
	CIQ2.11i_say_stop	55.747 <sup>i</sup>	5	11.149	2.772	.027
	CIQ2.11j_other	59.450 <sup>j</sup>	5	11.890	1.469	.216
	CIQ2.11a_goes_on_own_accord	780.007	1	780.007	131.711	.000
	CIQ2.11b_reassure_self	648.534	1	648.534	108.981	.000
	CIQ2.11c_seek_reassurance	527.620	1	527.620	96.922	.000
	CIQ2.11d_neutralize	1117.179	1	1117.179	141.686	.000
Intercept	CIQ2.11e_think_it_through	1028.987	1	1028.987	205.510	.000
	CIQ2.11f_replace_thought	693.860	1	693.860	131.083	.000
	CIQ2.11g_distract	688.213	1	688.213	168.801	.000
	CIQ2.11h_absorbing_activity	438.809	1	438.809	112.549	.000
	CIQ2.11i_say_stop	428.662	1	428.662	106.593	.000
	CIQ2.11j_other	370.274	1	370.274	45.758	.000
	CIQ2.11a_goes_on_own_accord	13.334	1	13.334	2.251	.140
	CIQ2.11b_reassure_self	1.340	1	1.340	.225	.637
	CIQ2.11c_seek_reassurance	5.277	1	5.277	.969	.329
	CIQ2.11d_neutralize	.320	1	.320	.041	.841
gender	CIQ2.11e_think_it_through	4.413	1	4.413	.881	.352
	CIQ2.11f_replace_thought	3.324	1	3.324	.628	.432
	CIQ2.11g_distract	.360	1	.360	.088	.768
	CIQ2.11h_absorbing_activity	1.071	1	1.071	.275	.603
	CIQ2.11i_say_stop	16.104	1	16.104	4.005	.051
	CIQ2.11j_other	4.957	1	4.957	.613	.437
	CIQ2.11a_goes_on_own_accord	45.263	2	22.631	3.821	.028
	CIQ2.11b_reassure_self	5.016	2	2.508	.421	.658
	CIQ2.11c_seek_reassurance	42.318	2	21.159	3.887	.027
	CIQ2.11d_neutralize	14.986	2	7.493	.950	.393
PRIMARY_DIAGNOSIS	CIQ2.11e_think_it_through	2.914	2	1.457	.291	.749
	CIQ2.11f_replace_thought	23.210	2	11.605	2.192	.122
	CIQ2.11g_distract	4.082	2	2.041	.501	.609
	CIQ2.11h_absorbing_activity	20.899	2	10.450	2.680	.078
	CIQ2.11i_say_stop	24.368	2	12.184	3.030	.057
	CIQ2.11j_other	32.803	2	16.402	2.027	.142
	CIQ2.11a_goes_on_own_accord	8.437	2	4.219	.712	.495
gender *	CIQ2.11b_reassure_self	.546	2	.273	.046	.955
PRIMARY_DIAGNOSIS	CIQ2.11c_seek_reassurance	10.767	2	5.384	.989	.379
	CIQ2.11d_neutralize	9.985	2	4.992	.633	.535

	CIQ2.11e_think_it_through	16.720	2	8.360	1.670	.198
	CIQ2.11f_replace_thought	1.896	2	.948	.179	.837
	CIQ2.11g_distract	1.672	2	.836	.205	.815
	CIQ2.11h_absorbing_activity	18.831	2	9.416	2.415	.100
	CIQ2.11i_say_stop	1.885	2	.942	.234	.792
	CIQ2.11j_other	12.828	2	6.414	.793	.458
	CIQ2.11a_goes_on_own_accord	302.029	51	5.922		
	CIQ2.11b_reassure_self	303.495	51	5.951		
	CIQ2.11c_seek_reassurance	277.631	51	5.444		
	CIQ2.11d_neutralize	402.129	51	7.885		
Error	CIQ2.11e_think_it_through	255.357	51	5.007		
	CIQ2.11f_replace_thought	269.957	51	5.293		
	CIQ2.11g_distract	207.931	51	4.077		
	CIQ2.11h_absorbing_activity	198.840	51	3.899		
	CIQ2.11i_say_stop	205.095	51	4.021		
	CIQ2.11j_other	412.690	51	8.092		
	CIQ2.11a_goes_on_own_accord	1415.000	57			
	CIQ2.11b_reassure_self	1155.000	57			
	CIQ2.11c_seek_reassurance	979.000	57			
	CIQ2.11d_neutralize	1992.000	57			
Total	CIQ2.11e_think_it_through	1600.000	57			
	CIQ2.11f_replace_thought	1235.000	57			
	CIQ2.11g_distract	1126.000	57			
	CIQ2.11h_absorbing_activity	811.000	57			
	CIQ2.11i_say_stop	792.000	57			
	CIQ2.11j_other	944.000	57			
	CIQ2.11a_goes_on_own_accord	361.930	56			
	CIQ2.11b_reassure_self	313.579	56			
	CIQ2.11c_seek_reassurance	338.982	56			
	CIQ2.11d_neutralize	434.035	56			
Corrected Total	CIQ2.11e_think_it_through	282.877	56			
	CIQ2.11f_replace_thought	314.982	56			
	CIQ2.11g_distract	214.000	56			
	CIQ2.11h_absorbing_activity	236.246	56			
	CIQ2.11i_say_stop	260.842	56			
	CIQ2.11j_other	472.140	56			

## Appendix U: Summary of ‘other’ responses to obsessions

Reclassification of ‘other’ responses – note, some participants described multiple responses falling into more than one category

What do you normally do when the thought occurs?	HC	ASD	OCD
I don't do anything, it goes of its own accord e.g. <i>"I let it run its course"</i>	0	1	0
I reassure myself by saying it doesn't mean anything	0	0	0
I seek reassurance from someone else e.g. <i>"Get someone to reassure me"</i>	0	0	1
I do something in my mind or in action to neutralize the thought e.g. <i>"Look at the switch and say "I've checked that" "wash" "Try to recall a positive interaction with the person to counterbalance the thought"</i>	2	3	4
I think it through e.g. <i>"I work through the scenario in my mind"</i>	0	1	2
I try to replace the thought by another	0	0	0
I try to distract myself with things around me	0	0	0
I throw myself into some absorbing activity e.g. <i>"I meditate" "exercise"</i>	1	2	1
I say "stop" to myself	0	0	0
Avoidance of triggers e.g. <i>"I look elsewhere" "Remove myself from the situation"</i>	0	1	1

## **Appendix V: Annual update to REC panel**

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**Appendix W: Presentation guidelines for Sage publications (including  
'Autism')**

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