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Abstracts

Systematic Review of the Literature:

Background: The National Institute for Health and Care Excellence (NICE) recommended psychological treatments for autistic young people with anxiety are largely un-inclusive of the population it serves, recommending similar interventions to neurotypical individuals, such as Cognitive Behavioural Therapy, with minor adaptations. Due to the nature of autism, it is possible that adaptations to the process and the content of CBT would be beneficial, however research considering which adaptations are most useful is lacking.

Objectives: This narrative systematic review aimed to explore the literature on effectiveness of adapted CBT on anxiety in autistic young people, and to examine which adaptations were used, and were most effective.

Method: Five electronic databases were searched, supplemented by backwards reference searching, forwards citating searching and contacting key authors. Inclusion criteria included participants aged five to 18 years old, with a diagnosis of autism, receiving a CBT-based adapted intervention and specifically measuring anxiety. Only English language papers from 2016 onwards were included. Data extraction (kappa=.87; .88) and quality assessment ratings (kappa=.86) were double coded with high interrater reliability

Results: Nineteen papers were included. The majority of papers found adapted CBT to be an effective intervention for autistic young people with anxiety. All papers implemented process level adaptations, and 12 of the 19 papers also included content level adaptations. The adaptations employed across papers was varied, and therefore it was not possible to conclude which were the most useful.

Conclusions: The variability in adaptations highlights the need for more guidance and

support for clinicians in order to provide the most effective intervention and ensure our services are inclusive and accessible. Further research should focus on exploring the impact of different levels of adaptations and producing clearer guidance.

Keywords: Autism, Anxiety, CBT, Therapy, Adaptations

Service Improvement Project:

Objective: COVID-19 brought many additional challenges for both staff and dementia patients in hospital. It is unclear what the impact may be on provision of care. This study aimed to explore staff's understanding of best practice care for this population, and to understand the impact of COVID-19 on providing this, as well as how it may have impacted incidents of challenging behaviour on the ward. Recommendations were reported.

Method: Staff confidence ratings and incidents of aggression and violence prior to, and during the first wave of the pandemic were reported. Interviews were conducted with seven staff members and analysed using content analysis. A dementia carer consulted on the development of the interview schedule.

Results: Incidents of challenging behaviour reduced during the pandemic. Seven themes were derived from the staff interviews: *Training feedback; change in incidents; managing challenging behaviours; adjusting care; toll on staff; no contact from relatives; and team support.*

Discussion: Staff reported to be largely following the NICE guidelines for supporting dementia patients displaying challenging behaviours. Many of these were unable to be implemented during the pandemic due to additional challenges. Staff discussed what additional support would be needed during this time to enable them to provide best practice care.

Keywords: Dementia, Delirium, COVID-19, healthcare, staff

Theoretically Driven Research Project

Background: Autism and trauma responses have significant diagnostic overlap, which can lead to misdiagnosis and delayed or inappropriate intervention. Research suggests that sensory modulation may differ in autism and trauma. However, there are no adolescent self-report measures available that explore sensory modulation in detail.

Objectives: The current study aimed to (a) develop a self-report adolescent sensory modulation questionnaire, and (b) explore any differences in the ways autistic young people, and young people who have experienced an adverse life event, modulate their sensory experiences.

Method: Questionnaire items were developed through literature searches and consultation with experts (n=7) and young people with sensory sensitivities (n=9). 507 young people completed the questionnaire, and an exploratory factor analysis was conducted to reveal the final subscales.

Results: EFA discovered three subscales within the measure; sensory-seeking, withdrawal, and interpersonal strategies. The measure had good internal consistency and divergent validity. Withdrawal significantly predicted autism scores, whilst withdrawal and sensory-seeking subscales significantly predicted ACE scores. Modulation subscales were significantly higher in the autism and trauma groups compared to controls. Withdrawal was approaching significance as higher in the autism group compared to the trauma group.

Key words: Sensory Modulation, Measure, Autism, Trauma, ACEs

Oxford Institute of Clinical Psychology Training

Critical Review of the Literature:

A systematic narrative review examining the effectiveness of adapted Cognitive Behavioural Therapy for anxiety disorders in young people with autism

Internal supervisor: Dr Fin Williams (University of Oxford)
External supervisor: Dr Joanne Cocksey (Oxford Health NHS Foundation Trust)

Word count: 6, 109

For submission at Review Journal of Autism and Developmental Disorders

Abstract

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Results: Nineteen papers were included. The majority of papers found adapted CBT to be an effective intervention for autistic young people with anxiety. All papers implemented process level adaptations, and 12 of the 19 papers also included content level adaptations. The adaptations employed across papers was varied, and therefore it was not possible to conclude which were the most useful.

Conclusions: The variability in adaptations highlights the need for more guidance and support for clinicians in order to provide the most effective intervention and ensure our services are inclusive and accessible. Further research should focus on exploring the impact of different levels of adaptations and producing clearer guidance.

Keywords: Autism, Anxiety, CBT, Therapy, Adaptations

Introduction

Autism Spectrum Disorder (ASD) is prevalent in around 0.6-1.0% of the child and adolescent population (Gillberg & Billstedt, 2000; Simonoff et al., 2008) and comorbid mental health difficulties are becoming increasingly more prevalent in this population in the UK (Langdon et al., 2013). In fact, 70-80% of children and adults with autism also experience mental health difficulties (Lever & Geurts, 2016), with anxiety and depression being the most prevalent (Strang et al., 2012). The consequences of this are great, with a high number of these individuals having additional suicidal thoughts, plans and attempts. One study screening individuals at the time of receiving an Asperger's diagnosis revealed that two thirds of those had experienced suicidal ideation, and a third had either planned or attempted to end their life (Cassidy et al., 2014). Additionally, childhood can be a very challenging time for those with autism due to increased rates of victimisation, lower social participation, and decreased quality of life with regards to psychological wellbeing, physical health, and social support (Crane et al., 2019). This highlights the importance of individuals receiving the most effective treatment available.

Cognitive Behavioural Therapy (CBT) is an evidence-based intervention used to treat a variety of mental health difficulties within the general population (Warmen et al., 2005). The cognitive model, initially developed by Beck (1964), suggests that emotions and behaviours are influenced by our interpretation of events. This model states that previous experiences can result in developing unhelpful assumptions and/or negative automatic thoughts which impact on the way we see the world, ourselves, others, and the future (Fenn & Byrne, 2013). CBT therefore uses cognitive and behavioural techniques to identify, appraise and adapt these distorted cognitions (Gaudiano, 2008).

Whilst this intervention has shown to be effective in the neurotypical population, there is debate as to whether CBT is the most appropriate intervention for individuals with people on the autism spectrum, due to the elements involved in this therapy. For example, rigidity of thinking within autism has been recognised as a barrier to accessing some of the cognitive aspects of CBT such as shifting a fixed negative world view (Cooper, Loades & Russell, 2018). CBT requires a degree of identifying emotions and cognitions in oneself and reframing these to consider alternative ways of conceptualising events. It has been argued that as some individuals with autism have difficulty with theory of mind (Baron-Cohen, 2001), this may also make this element of CBT more challenging (Donoghue, Stallard & Kucia., 2011). Equally, Donoghue et al. (2011) argued the need for 'increased emotional awareness, recognition and management', and 'problem solving skills' in effective CBT. This may also make it more difficult to access due to the difficulties associated with autism (Donoghue et al., 2011).

Nevertheless, there is some evidence for behavioural approaches for children with developmental disabilities (Howlin, 2006). Generally, NICE guidance does not differ for individuals with autism compared to neurotypical individuals, however there is a suggestion that modifications be made to the intervention. Despite this, there is no guidance for how to adapt CBT for the majority of disorders (Walters, Loades & Russell, 2016), and is only present for working with anxiety disorders. Even the guidance that is present largely focuses on the structure and method of delivery, such as more visual aids, regular breaks and incorporating special interests. The guidance lacks any advice on adapting the content of the intervention, which as we can see above are exactly the elements that research suggest might be more difficult to access for individuals with autism.

Importantly, clinician confidence in delivering CBT for individuals with an autism diagnosis is low. One study found that 64% of clinicians had not received appropriate knowledge or skills in this area (Cooper, Loades & Russell, 2018). Brookeman-Frazee et al. (2012) asked clinicians to comment on their perception of therapeutic gains within this population, and 54% stated it was not as effective as with typically developing individuals. Given the lack of concrete guidance for adaptations and low clinician confidence, it is necessary that interventions are reviewed to ensure the National Health Service (NHS) is providing the best possible care.

Crane and colleagues (2019) interviewed autistic adults regarding their mental health support, a key theme being barriers to support, particularly that services are not tailored to their individual needs which include their autism. They noted that when clinicians did not adapt their approach and consider what works and doesn't work for them, this usually resulted in withdrawing from service (Crane et al., 2019). For this reason, it is imperative that services can make adaptations to their approaches to make services and interventions accessible, and not exclude certain individuals from accessing appropriate therapy due to disability.

Previous reviews have shown adapted CBT to be an effective intervention for individuals with autism (such as Walters, Loades & Russell, 2016; Lang et al., 2010). These current reviews however are based heavily on 'high functioning' individuals, which is problematic as individuals with higher needs or those with additional learning disabilities are largely underrepresented in the literature. The current review will therefore address this by including papers that reflect the spectrum of individuals with autism accessing support, including those with learning disabilities.

Although the previous reviews' studies included some information regarding the modifications used, there were no conclusions drawn about which appeared to be most effective. The current review will explore what modifications were used, distinguishing between process level (i.e. practical modifications such as more written aids, regular breaks etc.) versus content level modifications (i.e. therapy components included such as additional relaxation techniques, reduced cognitive element etc.), and will comment on effect sizes when each or both of these were employed.

The current study will also include published papers where significant effects have not been present, as well as when they were, which is currently missing from the Walters et al. review. The previous review used The Newcastle-Ottawa Scale of assessment (NOS) (Wells et al., 2000) to assess the quality of included studies, however this tool has been shown to have low validity, perhaps due to a lack of comprehensive manuals in using the tool (Luchini et al., 2017). The tool's inter-rater reliability and ability to distinguish between low- and high-quality papers has also been questioned, which could threaten the conclusions made by the Walters et al. review. The current study will use the Downs and Black (1998) checklist, as this has shown good reliability and validity, and is also a more comprehensive quality assessment tool. This tool can also be used for both randomised and non-randomised studies, and therefore will allow appropriate comparisons across all included studies. Further to this, several additional studies have been conducted since the previous review on this topic in 2016.

The review explores the following research questions:

1. To what extent is adapted CBT for anxiety effective for children and young people with autism?

2. What modifications to CBT interventions for children and young people with autism were used most often, and which were associated with the best outcomes?
3. If there was a comparison intervention in the study, which was more effective?

4. What is the quality of the evidence for the effectiveness of CBT (with modification or without) for children and young people with autism?

Method

This literature review used a narrative systematic approach (Popay et al., 2006). Search terms (see appendix A) were entered across five different databases; PsychINFO, MEDLINE, PubMed, EMBASE and Scopus. Additional handsearching was completed via reference lists of included papers. In order to include unpublished work initiated from 2016, key authors were contacted. All retrieved references were downloaded to a reference management software, EndNote, and exported to Microsoft Excel. References were screened by title and abstract initially, and then further screened by full text.

Screening and selection

Studies were screened using the following inclusion criteria:

- English language papers
- Study date 2016 onwards (published or initiated)
- Participant age range between five to 18yrs
- Participants must have a diagnosis of autism
- Must be intervention study
- At least one intervention to be CBT based
- The intervention is specifically for anxiety disorders
- The CBT intervention included some autism related adaptations
- Studies must be case studies, Randomised Control Trials (RCTs), audits, service evaluations

Systematic reviews and dissertations were excluded from the review.

The initial literature search yielded 646 results. Searching the Open Science Forum, handsearching and contacting authors added an additional three papers. After duplicates were removed (n=329), the remaining 320 papers' abstracts and titles were screened against the inclusion criteria. 272 papers were excluded at this stage. The remaining 48 papers were screened against the inclusion criteria, leaving 19 papers to be included in the review (see figure one).

A proportion of papers were screened by another researcher to ensure reliability. A total of 54 abstracts (16.9%) and 16 full-texts (33.3%) were double screened, with high interrater reliability (kappa=.87, $p<.001$; kappa=.88, $p<.001$ respectively). Where disagreement occurred, this was discussed to reach a consensus.

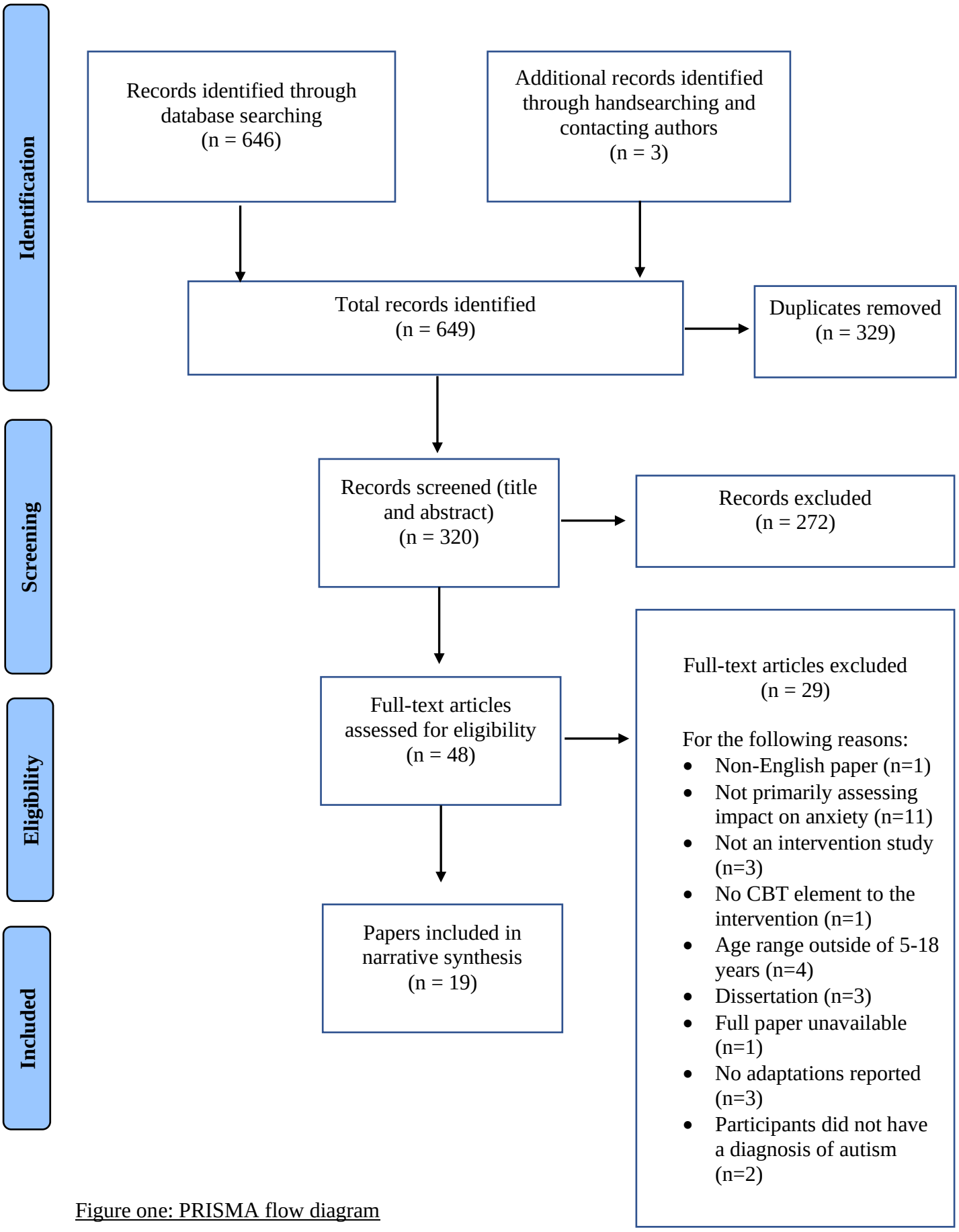

Figure one: PRISMA flow diagram

Data synthesis

Data were extracted from each of the included papers, including details of the adaptations used, and the overall effect of the intervention. Effectiveness was measured via quantitative change on anxiety-based measures, as well as any secondary impacts and qualitative acceptability of the intervention where it was reported (see table one). A second researcher duplicated 47% of data extraction to ensure accuracy.

Data were then synthesized based on the research questions; to what extent is CBT for anxiety effective, what modifications were used, and what was the impact of these?

Quality assessment

Quality assessment was completed for each paper, using the Downs and Black Checklist (1998) quality assurance tool (see appendix B). This tool is suitable for the review of both randomised and non-randomised studies, allowing the comparison of papers with a range of study designs. It has good reliability and validity (Downs & Black, 1998). Each paper was scored according to this checklist and given a total average score, calculated by removing the items that were not applicable. Interrater reliability was high (kappa=.86).

Results

Nineteen published articles were included in the review, with a range of study designs (see table one). All studies used an ABA design, with most including a follow-up period post intervention. Four studies were randomised control trials. A total of 53% (n=10) of the included interventions evaluated 1:1 CBT therapy, eight utilised group therapy formats (between two-seven+* members), and one intervention used both 1:1 and group therapy.

Sample sizes ranged from single cases to 166 participants. Five papers included young people with an IQ less than 70. Within the Moskowitz et al[1]. (2017) paper, all three participants were classified as functioning within the low range of intellectual and adaptive functioning according to screening measures, whilst Byrne et al. (2022) reported that only one participant had an IQ less than 70. Muskett, Radtke & Ollendick. (2020) recruited individuals with an intellectual disability. Solish et al. (2020) recruited 105 participants with IQ ranging 69-135 and noted that only four participants had an IQ under 80 (average range). It was not reported how many fell below 70, within the learning disability range. Similarly, Oerbeck et al. (2021) had an IQ range of 68-115 but did not comment on individual scores. No studies reported recruiting young people who attended Special Education Needs schools. All studies that did report school type of the young people reported that participants attended mainstream schools (n=6) or a correspondence based school (n=1).

[1] Assessed as borderline poor quality on the Downs and Black Checklist
*Byrne et al. (2022) did not report group sizes, but noted that a total of 21 participants attended one of three groups

Quality assessment

An assessment of quality identified nine papers deemed to be of 'fair quality' and nine papers of 'good' quality. One paper was bordering on 'poor quality' due to its increased risk of bias. This paper (Moskowitz et al., 2017) was included within the review, however its quality rating is discussed explicitly. Caution should be taken when drawing conclusions from this study. None of the included papers reached 'excellent' standard according to the Downs and Black Checklist (1998).

To what extent is adapted CBT for anxiety effective for children and young people with autism?

All included papers employed an adapted CBT based intervention. Across the 19 papers, 15 different interventions were implemented (see table one); some interventions were designed specifically for autistic young people, and others were adapted for this purpose.

Interventions ranged from four to eighteen sessions (mean = 10.79) of between 20 minutes and three hours (mean = 1.44 hours) in duration. Interventions also differed in the degree of parental involvement in the intervention. The majority of interventions were conducted face to face either in a therapeutic/research setting (n=11), or at school (n=3) however one study introduced an online game to be used independently by young people within their usual home setting (Carlier et al., 2020).

Studies varied in how they measured efficacy of the intervention, using a range of different anxiety-based outcome measures. The most commonly used measure was Spence's Children Anxiety Scale (SCAS) (n=8) which has both a child, parent and teacher reported version. All 8 studies utilised both the child and parent reported SCAS, whilst one used an additional

teacher version. Other studies utilised alternative outcome measures of anxiety to measure change over time (see table one). A high proportion of studies used parent and child reported outcomes (n=10), however other methods included gathering information from varying combinations of reporters, such as teachers, clinicians, young people and parents. Many papers used more than one measure of anxiety, and several used secondary measures exploring additional aspects such as social skills, and collected feedback regarding the acceptability of the intervention.

Table one:

Summary of included papers

Authors (date)	Location of study	Sample size	M:F ratio	Age range	IQ level (range)	School	Study design	Name of intervention	Type	Adaptations	Control	Anxiety based outcome measures used	Secondary measures	Direction of effect on anxiety	Effect size
Burke et al. (2017).†	Ireland	7	7:0	10-11	Average or above	Mainstream	Non-controlled study, pre-post	FRIENDS for Life	Group	Process Content	N/A	Children Beck Youth Anxiety Self-report Inventory (BAY-I)	Researcher observations, parental semi-structured interviews, child evaluation questionnaire	No change	N/A
Byrne et al. (2022) †	Ireland	21	17:4	5-11	<70-129	Unknown	Repeated group measure design	From Timid to Tiger	Group	Process Content	N/A	Anxiety Disorders Interview Schedule for DSM-IV (ADIS) Screen for child related anxiety disorders (SCARED) Spence's Children and Parent Anxiety Scale (SCAS), The Brief Assessment Checklist for Children (BAC-C), Strengths and Difficulties Questionnaire (SDQ) The Clinical Global Impressions Scale	Family Accommo-dation Scale (FAC)	Improvement on ADIS, SCARED, SCAS, GIS, and univariate effect only on BAC-C Non-significant improvement on BAC-C and SDQ at post or follow-up	ADIS: $\eta 2 = 0.76$ CRS Primary Anxiety diagnosis: $\eta 2 = 0.57$ SCARED: $\eta 2 = 0.28$ BAC-C: $\eta 2 = 0.30$ SDQ: $\eta 2 = 0.21$

† Studies deemed of 'fair' quality according to the Downs and Black Quality Tool

Carlier et al. (2020).§	Belgium	5	1:2	6-10	>70	Unknown	Usability study Non-controlled study, pre-post	Serious game: New Horizon	Individual	Process	N/A	Spence's Children Anxiety Scale (SCAS)	Pre-post interview, sessional mood rating	Parent report: Improvement for n=2 Child report: Improvement for n=2	N/A
Clarke et al. (2017). †	England	28	28:0	11-14	81 - 135	Mainstream	Multiple baseline experimental design	Attwood's exploring feelings: CBT to Manage Anxiety	Individual	Process	Waitlist	Spence's Children and parent Anxiety Scale (SCAS)	Coping Scale for Children and Youth, Interviews	Improvement in child and adult rated at post and FU	Child - d=.72, Parent - d=.69
Drmic et al. (2017). §	Singapore	44	38:6	13-15	Average or above	Mainstream	Non-controlled study, pre-post Feasibility	Face Your Fears - School Based Program	Group	Process Content	N/A	Screen for child related anxiety disorders (SCARED)	Developmental behavioural checklist-teacher (DBC-T), semi-structured parent interview	Improvement	*r* = 0.85
Hamatani et al. (2020).†	Japan	1	0:1	17 years	81	Correspondance based school	Case study	CBT	Individual	Process	N/A	Panic Disorder Severity Scale (PDSS)	N/A	Improvement	N/A
Higgins et al. (2019) §	Ireland	12	10:2	9-12	80-119	Unknown	Non-controlled study, pre-post Exploratory	SPECIAL Friends	Group	Process Content	N/A	SCAS	Parent feedback forms, semi-structured parent interviews	Improvement	Child Total anx score g=1.2, Sep Anx g=.98 , Parent total anx score g=.62; Sep Anx g=.46 OCD g=.98
Kilburn et al. (2019) §	Denmark	9	7:2	9-13	>70	Unknown	Non-controlled study, pre-post	Cool Kids ASD Programme	Group	Process Content	N/A	SCAS, Anxiety Disorders Interview Schedule for DSM-IV: Parent & Child interview schedule (ADIS/CP)	Child Anxiety Life Inference Scale (CALIS), Children's Automatic Thoughts Scale (CATS),	Improvement	ADIS/CP-CS: Pre-post: d=1.25, post-FU d=.46. All anx diagnoses pre-post d=1.70, post-FU d=.23. SCAS child pre-post d=.71; parent d

§ Studies deemed of 'good' quality according to the Downs and Black Quality Tool
† Studies deemed of 'fair' quality according to the Downs and Black Quality Tool

													Experience of Service Questionnaire		= .67), post-FU - child (d=.00), parent (d = –.00).
Kilburn et al. (2020) §	Denmark	49	28:21	8-14	>70	Unknown	RCT	Cool Kids ASD Programme	Group	Process Content	Waitlist	ADIS/CP - Anxiety and Depression scales only, SCAS	Child Anxiety Life Inference Scale (CALIS), Children's Automatic Thoughts Scale (CATS), Experience of Service Questionnaire	Improvement on anxiety symptoms/diagnosis	Severity CBT group: pre-post d=1.05, WL group d=.71. No. of Dx's: CBT group d=.59. SCAS-CBT Parent pre-post d=.56, child pre-post d=.33
Luxford et al. (2017) †	England	35	31:4	11-15	>70	Mainstream	RCT	Exploring Feelings	group (4-6)	Process Content	Waitlist	School Anxiety Scale, SCAS, Social Worries Scale	Social Responsiveness Scale, Attentional control task (Flanker task), Attention to Threat task (Emotional Stroop)	Improvement in CBT group	Pre-post: Parent n2p=.18, child n2p=.23, teacher n2p=.24 Group x Time interaction parent n2p=.41, child n2p=.12, teacher n2p=.14).
Maskey et al. (2019). †	England	8	8:0	8-12	no reported LD'	Unknown	Non-controlled study, pre-post Observational study	None given	1:1	Process	N/A	SCAS, 'target behaviours'	Confidence ratings	Functional ability: Improvement for n=4 SCAS Clinical range: : Improvement for n=1 (parent-report only)	N/A

§ Studies deemed of 'good' quality according to the Downs and Black Quality Tool
† Studies deemed of 'fair' quality according to the Downs and Black Quality Tool

Mosko witz et al. (2017).*	USA	3	3:0	6,8 and 9	Low range of intellect ual and/or adaptive function ing;	Unknow n	Case series	None given	1:1	Process Content	N/A	Behavioural observation,, heart rate and respiratory sinus arrhythmia, parent-report and blind observer Likert-type ratings	N/A	Improvement	N/A
Murphy et al. (2017). †	England	36 (17 CBT, 19 counsell ing)	22:14 (CBT-10:7, couns elling-12:7)	12-18	>70	Mainstr eam	Pilot RCT**;**	Multimodal Anxiety and Social Skill Intervention for adolescents with ASD (MASSI, White et al. 2010)	Group and 1:1	Process Content	NHS Counsel ling	Anxiety Disorders Interview Schedule for Children/Parents, Child and Adolescent Symptom Inventory-4 ASD Anxiety Scale	Social Responsivene ss Scale (SRS), Therapy Process Observational Coding System—Alliance Scale	No improvement (Only improvement Sep Anx at post, not FU).	N/A
Muskett et al. (2020) †	USA	1	1:0	8	Intellect ual disabilit y	Mainstr eam	Case study	OST	1:1	Process Content	N/A	ADIS-P-5, CBCL, MASC, BAT	N/A	Improvement	N/A
Oerbeck et al., (2021). §	Norway	10	8:2	8-12	68-115	Unknow n	Pilot study, non-controlled O pre-post	"Less Stress"	1:1	Process Content	N/A	Revised Child Anxiety and Depression Scale (RCADS)	SRS Schedule for Affective Disorders and Schizophrenia for School-Aged Children: Present and Lifetime Version (K-	Improvement	N/A

* Studies deemed of borderline 'poor' quality on the Downs and Black Quality Tool
† Studies deemed of 'fair' quality according to the Downs and Black Quality Tool
§ Studies deemed of 'good' quality according to the Downs and Black Quality Tool

													SADS-PL DSM5) Children's Global Assessment Scale (CGAS) The Child Anxiety Life Interference Scale (CALIS) Inventory of Life Quality in Children and Adolescents (ILC)		
Ollendick et al. (2021) §	USA	9	9:0	6-14	79-121	Unknown	Non-current multiple baseline	One Session Treatment for Specific Phobia	1:1	Process	N/A	ADIS for DSM-IV BAT	Satisfaction questionnaire	Improvement on ADIS (child and parent) and parent reports of fear No change on BAT	ADIS: Parent CSR W=0.58, Child CSR W=0.53 BAT with parent w=0.11, BAT alone W=0.03; Parent Fear Rating W=0.45
Solish et al. (2020). †	Canada	105	76:29	6.9-15.3	69-135 (only 4ppts had IQ of <80 (average)	Unknown	Non-controlled study, pre-post	Facing your Fears	Group (3-5 parent /child dyads)	Process	N/A	SCAS, BASC-2, Group questionnaires designed by study	Satisfaction questionnaire	Improvement	Parent Report SCARED d=.67, SCAS d=.52 BASC-2 Externalisind=.24, Internalisingd=.51, BSI d=.41 Parent questionnaire: Effective d=-1.14, Avoidance d=.48, Interferenced=.59

§ Studies deemed of 'good' quality according to the Downs and Black Quality Tool
† Studies deemed of 'fair' quality according to the Downs and Black Quality Tool

															Family impact d=.53 (M) Child Report SCARED d=.36, SCAS d=.37. Child Q non significant
Storch et al. (2020). §	USA	32	26:6	6-17	>70	Unknown	Multiple baseline experimental design	Family-based Exposure-focused treatment (FET)	1:1 (child and parent)	Process	TAU	PARS, ADIS-IV-C/P, CGI-S/CGI-I, CAIS-P, MASC-P, CSDS-P	SACA, SRS, (CBCL),	Improvement	PARS pre-post d=1.01, 2m d=0.35, ADIS CSR-pre-pos d=1.11, 2m d=0.82, CGI-S pre-post d=1.22, 2m d=0.46 (M), CAIS-P total score pre- post d=1.04, 2m d=-.20, MASC-P pre-post d=0.54, 2m=0.65, SSDS pre-post d=.84, 2m d=.36
Wood et al. (2020) §	USA	166	34:132	7-13	>70 - MEAN IQ: BIACA 102.79, CC 101.64, TAU 102.35	Unknown	RCT	Behavioural Interventions for Anxiety in Children with Autism (BIACA)	Individual	Process Content	Coping Cat (no adapations) and TAU	PARS, CGI-I, CAIS	Child Behaviour Checklist, SRS	Improvement	PARS: BIACA > CC d=.63; BIACA > TAU d=1.69 CAIS School: BIACA>TAU d=.75; CAIS Social BIACA>CBT d=.28 BIACA>TAU d=.54

§ Studies deemed of 'good' quality according to the Downs and Black Quality Tool

Effectiveness of CBT on anxiety

Overall, the majority of studies (n=16) reported a reduction in anxiety as measured by the anxiety-specific outcome measures. Studies which reported effect sizes (n=11) ranged from small – very large. These papers employed a range of intervention programmes, with varying levels of parental involvement and utilisation of 1:1 and group therapies.

Papers that found no effect of the CBT intervention on anxiety scores utilised three different interventions; the Friends for Life intervention (Burke, Predeville & Veale, 2017), a virtual reality game (Maskey et al., 2019), and MASSI (Multimodal Anxiety and Social Skill Intervention for adolescents with ASD) (Murphy et al., 2017). Although no impact on anxiety was found, Burke et al. (2017) showed an increase in confidence ratings in seven of the eight participants, and within Maskey et al. (2019), six of the seven participants reported learning about their feelings.

Secondary Measures and Additional Gains

Many papers found that the adapted CBT intervention showed additional benefits such as reductions in behavioural avoidance, problem solving, cognitive avoidance, assistance seeking, (Clarke, Hill & Charman., 2017), increased understanding of students (Drmic, Aljunied & Reaven, 2017), 'interference' on parent and child's life (Kilburn et al., 2020; Oerbeck et al., 2021), social responsiveness (Luxford, Hadwin & Kovshoff., 2017; Wood et al., 2020), attentional control (Luxford et al., 2017), family accommodation of anxiety (Byrne et al., 2022), depression and internalising (Wood et al., 2020).

Acceptability

In nine of the studies, young people and/or parents were asked to provide feedback regarding the intervention. Feedback was generally positive on the enjoyment or satisfaction of the

intervention (Clarke et al., 2017; Drmic et al., 2017; Higgins et al., 2019; Kilburn et al., 2019; Solish et al., 2020) as well as the impact on anxiety symptoms (Clarke et al., 2017, Drmic et al., 2017, Higgins et al., 2019, Kilburn et al., 2019; Kilburn et al., 2020; Muskett et al., 2020; Ollendick et al., 2021.), emotional wellbeing (Drmic et al., 2017, Kilburn et al., 2019) and behaviour (Clarke et al., 2017, Drmic et al., 2017). Only one study reported negative feedback (namely the computer games being "too boring" or too challenging (Carlier et al., 2020).

Barriers and positive aspects of interventions

Four papers also explored what was helpful about the interventions, and what the barriers were. Positive attributes of the interventions included the group dynamics (Clarke et al., 2017, Kilburn et al., 2019), being around and making connections with others with similar difficulties (Higgins et al., 2019, Kilburn et al., 2019). Some found the resources helpful (Drmic et al., 2017, Higgins et al., 2019, Kilburn et al., 2019) in addition to the parental involvement (Higgins et al., 2019, Kilburn et al., 2019). Other benefits included strong and consistent support from stakeholders, joint planning sessions and selecting motivated young people for the intervention, as well as having skilled facilitators and optimising the structure of the intervention (Drmic et al., 2017). One paper reported participants valued having opportunities for social interactions (Higgins et al., 2019), the helpful exercises, being able to amend the material, and the use of repetition to enhance understanding (Kilburn et al., 2019).

Barriers to the intervention included the physical environment (Clarke et al., 2017), scheduling difficulties/logistics (Drmic et al., 2017, Higgins et al., 2019), lack of parental support, and individuals not being ready for the group. Some noted the difficulties selecting fears and designing the hierarchies to work on, as well as the absence of locally developed resources, and having a lack of knowledge and skills (Drmic et al., 2017). One paper reported a barrier to their intervention was children finding it challenging to discuss elements of this with their

parents (Higgins et al., 2019). Another paper revealed barriers in pitching the homework too high, or the material too low, being too repetitive, and reported that the group treatment triggered anxiety/school refusal (Kilburn et al., 2019).

If there was a comparison intervention in the study, which was more effective?

The majority of the studies (n=13) evaluated the effectiveness of CBT on a single group. Six studies however used a comparison group. One compared CBT to NHS based counselling, one compared BIACA (an adapted CBT approach) to Coping Cat (unadapted) and a Treatment as Usual (TAU) group. The remaining four papers used either a waitlist (n=3), or TAU (n=1) control group. All four of these (Clarke et al., 2017; Kilburn et al., 2020; Luxford et al., 2017; Storch et al., 2020) found that CBT was superior to waitlist/TAU in reducing anxiety, although Kilburn et al. (2020) had mixed results. They found no statistically significant differences between groups in remission rates or severity ratings following the intervention, as both the control and CBT group showed a significant reduction in anxiety. However, the number of anxiety diagnoses significantly reduced in the CBT group but not the waitlist group. When measured by the SCAS, they found a greater reduction in anxiety in the CBT group when compared to the waitlist group.

Murphy et al. (2017) compared CBT to a counselling intervention and examined Clinical Severity Ratings for four anxiety types (separation, social, generalised and specific phobias) and the Child and Adolescent Symptom Inventory-4 at pre and post intervention. No significant differences were found between groups post intervention except for separation anxiety at post-intervention. This difference however was not maintained at 12-week follow up.

Wood et al. (2020) compared two different CBT interventions, one adapted for autistic individuals, and one unadapted. The adapted intervention (BIACA) produced higher reductions on the Paediatric Anxiety Rating Scale (PARS) and on the social subscale of the Child Anxiety Impact Scale (CAIS) than the unadapted CBT intervention (Coping Cat) and TAU control group. Although both interventions produced better results in comparison to the TAU group on the Clinical Global Impression-Improvement Scale and the CAIS school subscale, the CBT interventions did not differ from each other on these measures.

What modifications to CBT interventions for children and young people with autism were used most often, and which were associated with the best outcomes?

Process level adaptations

Process level adaptations appeared in all 19 of the included papers, although the range of adaptations that were utilized varied across studies (see table two). The most frequently used process level adaptations included using visual aids to support understanding (n=8), increased use of parental involvement in the intervention (n=7), and the use of hands-on activities and props (n=5). Other adaptations included tailoring the language, repetition of key messages, movement breaks, multiple choice questions and social stories. Two papers also used a computer based/virtual reality intervention.

Although many of the papers included process level adaptations, only seven used these exclusively (i.e. included no content level adaptations). The absence of content level adaptations did not appear to prohibit the intervention from being effective, as six of the seven papers showed some level of reduction in anxiety scores post-intervention.

Two papers employed the use of a computer-based game to deliver CBT elements. One of these however (Carlier et al., 2020), although described as a CBT-based intervention, only applied relaxation, breathing techniques and guided imagery. It also lacked a therapeutic element and was a computer-based game children were encouraged to play alone as part of their daily activities. Due to this, parents often did not record their child's use of the game, and encouraged its use during a calm period, not practicing the skills when the authors intended.

The second study used virtual reality technology to immerse young people into feared situations virtually, controlled by the psychologist, using gradual exposure. In contrast to the previous paper, this study utilised a wider range of CBT strategies including psychoeducation, identifying feelings, relaxation techniques and cognitive restructuring (Maskey et al., 2019). Interestingly, both papers that used technology-based CBT showed mixed results. The former paper had two dropouts, one due to the game being not stimulating enough, and of the final three individuals, two showed reductions in anxiety. In this latter study, only four of the seven children who completed the follow up measures showed a reduction in anxiety, and one showed an increase in anxiety. Some provided their feedback on the first paper's intervention and described the relaxation games as "too boring" or "too challenging". For the second paper however, seven of eight participants showed an improvement in confidence.

The additional five papers that employed process only adaptations included adaptations to the format of the content (i.e. hands-on activities, frequency/duration of sessions, emphasis on rewards, increased parental involvement, inclusion of strengths/special talents), and adaptations to the way the information was communicated (i.e. repetition, tailored language, visual aids and summaries, social stories, multiple choice/closed questions). Adaptations employed differed across papers. All five studies reported an improvement in anxiety scores on at least one measure with effect sizes ranging from small to large. Clarke et al. (2017) also

found a significant reduction in behavioural avoidance, cognitive avoidance, behavioural avoidance and improved problem-solving at follow-up. Parents and young people were interviewed for feedback, and parents reported that their children showed increased engagement in thought and management of emotional responses, and a reduction in behavioural difficulties. Young people also report the intervention helped with processing complex emotions through learning skills to develop emotional self-awareness, make sense of their emotions and link and change their thoughts and behaviours. Solish et al., (2020) and Ollendick et al. (2021) measured high parental satisfaction with the intervention their child received.

Content level adaptations

Of the 19 included papers, 12 employed content level adaptations. These included simplified cognitive elements and a larger emphasis on behavioural techniques (n=5), as well as recognising emotions (n=1). Other adaptations included additional components within the intervention such as social skills (n=6), disruptive behaviour (n=1), and theory of mind skills (n=1).

None of the studies used content level adaptations in isolation, and all included at least some additional process level adaptations. Therefore, it was not possible to consider the potential impact of content level adaptations in isolation on anxiety outcomes.

Both process level and content level adaptations

The majority of papers employed adaptations at both the process and content level. Different combinations of adaptations were used across the different papers. These were clustered into themes and are represented in table two.

Table two:

Process level and content level adaptations across all studies

Paper	Process level adaptations	Content level adaptations
Burke et al., 2017	• Environmental zones • Emphasis on visuals • Structure and routine • Movement breaks and sensory tools provided • Use of puppets and props, role plays, • Transition activity to settle anxiety before group starts	• Emphasis on ToM during all course objectives (recognising feelings in others and self)
Byrne et al., 2022	• Intervention delivered through parent/s • Parents given opportunities to implement modifications to behavioural experiments in line with Walters et al., 2016 (e.g. metaphors, repetition, social stories, modelling etc.)	• Increased emphasis on behavioural strategies, and less on cognitive strategies
Carlier et al., 2020	• Computer game to be accessed at any time and place • No face to face therapy	• N/A
Clarke, C., et al., 2017	• Incorporation of strengths and special talents • Social stories	• N/A
Drmic et al., 2017	• Visual supports • Multiple choice • Hands on activities e.g. video modelling. • Worksheets created specifically for the school setting and older ppts. • Some adaptations to make culturally appropriate (e.g. change of video example)	• Increased emphasis on emotion regulation and distinguishing between "real fears" and "false alarms".
Hamatani et al., 2020	• Visual aids • Multiple choice/closed questions • Repetition • Modelling • Online summary of session • Shorter and less frequent sessions	• N/A
Higgins et al., 2019	• Parental psychoeducation sessions • Flexibility in delivery appropriate to group's needs, interests and learning styles.	• Social skills
Kilburn et al., 2019	• Adaptation to duration and number of sessions • Visual aids • Structured worksheets	• Cognitive restructuring was 'markedly simplified' • Larger emphasis on relaxation and exposure • Less emphasis on communication skills and abstract thinking

		• Social skills
Kilburn et al., 2020	• Visual aids • Structured worksheets	• Cognitive restructuring was 'markedly simplified' • Larger emphasis on relaxation and exposure • Less emphasis on communication skills and abstract thinking • Social skills
Luxford et al., 2017	• Comic strip conversations • Visual aids • Using examples from special interests.	• Discussion of emotions in social context
Maskey et al., 2019	• Exposure tasks completed virtually, controlled by psychologist	• N/A
Moskowitz et al., 2017	• Social stories • Video modelling	• Reduced focus on cognitive restructuring
Murphy et al., 2017	• Increased family involvement (Family members the focus of the intervention; Practicing skills with siblings and parents) • Regular practice of skills through roleplay and exposure exercises. • Immediate, direct and specific feedback on performance and effort – from therapist and from parents	• Social skills strategies – with focus on family relationships
*Muskett et al., 2020	• Increased parental involvement (gradually taking over as the primary coach for exposure work)	• No cognitive element
Oerbeck et al., 2021	• Visual aids • Modelling using a fictional character • Tailored language • Hands on activities (games/roleplays) • Special interests incorporated • Frequent breaks • Shorter sessions • Rewards for attendance • Repetition of material at home	• Social skills training
Ollendick et al., 2021	• Longer booster sessions to support with generalisation of material • Increased parental involvement • Visual aids • Special interests incorporated	• N/A
Solish et al., 2020	• Visual aids • Multiple choice questions • Hands-on activities e.g. video modelling	• N/A
Storch et al., 2020	• Tailored language • Emphasis on rewards • Increased parental involvement	• N/A
Wood et al., 2020	• Use of modular format guided by an algorithm to personalise treatment	• Disruptive behaviour • Social engagement skills

	• Special interests incorporated into treatment to promote engagement. • Target behaviours reinforced with reward system at home and school.	

**Screened as borderline poor quality on the Downs and Black quality assessment tool.*

Across all 12 papers, 10 of these showed an improvement in anxiety. Burke et al. (2017) reported no change in anxiety, although this paper did not employ any statistical analyses due to its small sample of seven. The Murphy et al. (2017) study, a pilot RCT, also found non statistically significant difference in anxiety scores between a CBT and counselling intervention at post-intervention (except for separation anxiety on the CSR measure) and at follow-up (all subscales of both the CSR and CASI-R). The adaptations these two papers employed did not appear to differ substantially from those that found CBT to be an effective intervention for reducing anxiety symptoms. For example, although neither Burke et al. nor Murphy et al. simplified the cognitive element of their CBT intervention, which many other papers did, this was not exclusive to these papers. Others who also did not report a simplified cognitive element found a significant difference in their anxiety scores pre and post.

The remaining ten papers that reported the use of both process level and content level adaptations within their CBT intervention found an overall reduction in anxiety. Eight of those conducted statistical analyses on their data, and of those who did report effect sizes, all[*] reported large to very large effect sizes in at least one anxiety measure when comparing anxiety pre and post intervention. Kilburn et al. (2019), analysing a Cool Kids ASD programme, found large effect sizes at post intervention, but these reduced to small to medium effects at follow-up. Kilburn et al. (2020) also found a large effect size (d = 1.05) when comparing anxiety severity pre-post, however a medium-large effect was also found in the waitlist group (d =

[*] Oerbeck et al. (2021) did not report any effect sizes

0.71). This was not replicated in other results however as they found the number of anxiety diagnoses reduced following the intervention in the CBT group (medium effect size) but not the waitlist group, and improvements were statistically significantly larger in the CBT group for child and parent SCAS scores. Analyses of completers only produced even more positive results.

Wood et al. (2020) compared two CBT interventions, one with adaptations (BIACA) and one without (Coping Cat), with a TAU group. Interestingly, although both interventions outperformed the TAU group, BIACA was only shown to be superior to Coping Cat in some measures (PARS; CIAS social subscale) but not others (Clinical Global Impression; CIAS school subscale).

Due to the range of adaptations applied across all included papers it is not possible to conclude which adaptations may have been the most helpful in supporting young people on the autism spectrum to access CBT interventions. However, broadly the use of both process and content level adaptations together produced positive reductions in anxiety.

Discussion

This review aimed to examine the effectiveness of CBT interventions on anxiety for young people on the autism spectrum, exploring the adaptations employed and the effect of these. Although findings were not consistent across papers, the majority found adapted CBT to be an effective intervention for this population, and superior to waitlist, TAU, counselling and unadapted CBT. Moreover, children and parents appeared satisfied with this method of treatment overall.

As previously mentioned, the guidance for adapting evidence-based interventions for young autistic people is sparce, which has resulted in a lack of clinician confidence (Cooper, Loades & Russell, 2018). This was highlighted within this review, with every paper employing a different set of adaptations to their CBT intervention. Interestingly, no included papers employed content only adaptations, suggesting that clinicians/researchers were most likely to utilise process level adaptations such as pacing, breaks and visual material. Most papers also employed content level adaptations in addition to process adaptations, however these varied so widely that it was not possible to distinguish which may have had the most benefit.

Both CBT adapted at the process level only, and CBT adapted at process and content level appeared to be effective, although effect sizes appeared higher where both types of adaptations were implemented. Clinicians providing this therapy should therefore take this into consideration when planning their intervention with their young people, and may wish to consider implementing both types of adaptations to ensure the most success in their intervention.

The variability in the specific adaptations across papers means it was not possible to make conclusions about the most effective adaptations, and those that may not add additional benefit. There is a need for more concrete guidance on this topic to ensure interventions are inclusive and accessible to the individuals they intend to support, and therefore further research is needed. In the interim, this paper highlights the importance of collaboration in therapeutic work and gaining feedback at regular intervals from the autistic young people receiving therapy to ensure the intervention is being tailored in the most helpful way for the young person. It may be helpful for clinicians to review the possible adaptations used across the many papers to determine with their young people and families what may be the most useful for them on an individual basis.

Achieving a balance between implementing the 'core' elements of the evidence-based intervention, and adapting the treatment to fit the client can be challenging for clinicians to achieve, particularly within the context of service resource (Mignogna et al., 2018). To support clients using a person-centred approach, it is expected clinicians will adapt the intervention in line with clients' needs, wishes and abilities. However, the wide variability demonstrated within the current review highlights the lack of guidance and evidence-base on the most effective adaptations.

Further research should focus on exploring the effect of specific adaptations, including process and content level adaptations, using meta-analyses and RCTs. This would enable the development of much needed suitable guidance that considers both the process and the content of the intervention. This research should attempt to include more of the grey literature to identify those adaptations that may not have been successful. It may be useful to also compare these studies to those who have not employed any adaptations to further ensure the efficacy of

the adapted intervention. Including the voice of autistic young people should also be prioritised in developing NICE guidance, and therefore future research should include gaining the views of autistic young people who have received CBT for anxiety to explore which adaptations they have found most useful. Research should continue recruiting autistic young people with an additional intellectual disability, as an underrepresented group in the literature despite making up approximately 70% of the autistic community (Mefford et al., 2012; Newschaffer et al., 2007; Wilkins and Matson, 2009). This may allow for a more thorough exploration of content level adaptations, where these may be even more relevant.

Limitations

This review attempted to be inclusive of unpublished work in order to reduce publication bias, and to broaden the population to include autistic young people with an intellectual disability. It was noted however that very few included papers recruited autistic individuals with an IQ of less than 70. In addition, authors were contacted in an attempt to include unpublished work, however only one additional study was returned. This review therefore may be subject to publication bias, and additional work where adaptations have not been successful were missed.

This research hoped to collate and explore different adaptations to CBT for anxiety for young people on the autism spectrum, however the information reviewed was based on what was reported in the individual papers. It is possible that additional adaptations were employed and not reported explicitly due to the nature or quality of the paper. The review also focused on employed adaptations in order to focus on those most effective, however it did not consider

the effect of CBT in the absence of adaptations. This may have been a helpful addition to the review in formulating conclusions.

The Downs and Black quality assessment tool was used to provide a quality score for each paper. This was chosen due to its ability to assess a range study methodologies and designs. A significant proportion of the included studies were single-group pre-post design, which can be problematic within systematic reviews (Paulus, Dahabreh, Balk, Avendano, Lau & Ip 2014). Due to the nature of these studies, a number of the Downs and Black items were not applicable, such as those relating to comparison groups. A sum total was calculated accounting for those not applicable, however it should be noted that this was a limitation of the measure used. Alternative measures were explored; however no suitable alternative was found. This is a recognised limitation of the inclusion of single-group designs.

Despite the limitations, this review has highlighted the different levels of adaptations being employed across services when delivering CBT for anxiety with the autistic population. The lack of consistency in adaptations across papers further demonstrates that this population continues to be underrepresented, and outlines the need for further guidelines for clinicians, and research into this area. It is important that this research involves the voices of the young autistic people who are receiving these interventions.

References

Beck, J. S. (1964). *Cognitive Therapy: Basics and Beyond.* New York: Guildford Press.

Brookman-Frazee, L., Drahota, A., Stadnick, N. and Palinkas, L. A. (2012). Therapist Perspectives on Community Mental Health Services for Children with Autism Spectrum Disorders. *Administration and Policy in Mental Health and Mental Health Services Research, 39,* 365-373.

Burke, M.-K., Predeville, P & Veale, A. (2017). An evaluation of the "FRIENDS for Life" programme among children presenting with autism spectrum disorder. *Educational Psychology in Practice 33*(4), 435-449.

Bury, S. M., Jellett, R., Spoor, J. R. & Hedley, D. (2020). "It Defines Who I Am" or "It's Something I Have": What Language Do [Autistic] Australian Adults [on the Autism Spectrum] *J Autism Dev Disord*, 2020-02-28. https://doi.org/10.1007/s10803-020-04425-3

Byrne, G., Ghráda, A.N., & O'Mahony, T. (2022). Parent-Led Cognitive Behavioural Therapy for Children with Autism Spectrum Conditions. A Pilot Study. *Journal of Autism and Developmental Disorders*, 2022-02-12. https://doi.org/10.1007/s10803-022-05424-2.

Carlier, S., Van der Paelt, S., Ongenae, F., De Backere, F. & De Turck, F. (2020). Empowering children with ASD and their parents: Design of a serious game for anxiety and stress reduction†. *Sensors (Switzerland) 20*(4), 966.

Cassidy, S., Bradley. P., Robinson, J., Allison, C., McHugh, M and Baron-Cohen, S. (2014). Suicidal ideation and suicide plans or attempts in adults with Asperger's syndrome attending a specialist diagnostic clinic: a clinical cohort study. *The Lancet Psychiatry, 1*(2): 142–147.

Clarke, C., Hill, V. & Charman, T. (2017). School based cognitive behavioural therapy targeting anxiety in children with autistic spectrum disorder: a quasi-experimental randomised controlled trail incorporating a mixed methods approach. *J Autism Dev Disord, 47*(12), 3883-3895.

Cooper, K., Loades, M. E., & Russell, A. J. (2018). Adapting Psychological Therapies for Autism - Therapist Experience, Skills and Confidence. *Research in autism spectrum disorders, 45,* 43–50. https://doi.org/10.1016/j.rasd.2017.11.002

Crane, L., Adams, F., Harper, G., Welch, J., & Pellicano, E. (2019). 'Something needs to change': Mental health experiences of young autistic adults in England. *Autism, 23*(2), 477-493. https://doi.org/10.1177/1362361318757048

Donoghue, K., Stallard, P. and Kucia, J. (2011). The clinical practice of Cognitive Behavioural Therapy for children and young people with a diagnosis of Asperger's Syndrome. *Clinical Child Psychology and Psychiatry, 16*(1), 89-102.

Downs, S. H. and Black, N. (1998). The feasibility of creating a checklist for the assessment of the methodological quality both of randomised and non-randomised studies of health care interventions. *J Epidemiol Community Health, 52,* 377-382.

Drmic, I. E., Aljunied, M. & Reaven J. (2017). Feasibility, Acceptability and Preliminary Treatment Outcomes in a School-Based CBT Intervention Program for Adolescents with ASD and Anxiety in Singapore. *J Autism Dev Disord 47*(12), 3909-3929.

Fenn, K. and Byrne, M. (2013). The key principles of cognitive behavioural therapy. *InnoAiT: Education and Inspiration for General Practice, 6*(9), 579-585. https://doi.org/10.1177/1755738012471029

Gillberg, C., & Billstedt, E. (2000). Autism and Asperger syndrome: Coexistence with other clinical disorders. *Acta Psychiatrica Scandinavica*. https://doi.org/10.1034/j.16000447.2000.102005321.x

Gaudiano, B. A. (2008). Cognitive Behavioral Therapies: Achievements and Challenges. *Evid Based Ment Health, 11*(1): 5-7. https://doi.org/10.1136/ebmh.11.1.5.

Hamatani, S., Matsumoto, K & Shirayama, Y. (2020). Blended cognitive behavioural therapy for adolescents with panic disorder co-morbid with autism spectrum disorder: A case study. *The Cognitive Behaviour Therapist, 13*(37), 1-13.

Higgins, E., Slattery, C., Perry, J. L. & O'Shea. (2019). An evaluation of a group CBT programme for children with a diagnosis of autism spectrum disorder in a school age disability service. *Educational Psychology in Practice 35*(1), 50-66.

Howlin, P. (2006). Autism spectrum disorders. *Psychiatry*, *5*(9), 320–324.

Irons, J. Y., Sheffield, D., Ballington, F. & Stewart, D. E. (2019). A systemic review on the effects of group singing on persistent pain in people with long-term health conditions. *European Journal of Pain, 24*(1), 71-90.

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. Autism, 20(4), 442–462. https://doi.org/10.1177/1362361315588200

Kilburn, T. R., Sorensen, M. J., Thastum, M., Rapee, R. M., Rask, C. U., Arendt, K. B & Thomsen, P. H. (2019). Group-based Cognitive Behavioural Therapy for Anxiety Disorder in Children with Autism Spectrum Disorder: a feasibility study. *J Psychiatry 73*(4-5), 273-280.

Kilburn, T. R., Sorensen, M. J., Thastum, M., Rapee, R. M., Rask, C. U., Arendt, K. B., Carlsen, A. H. & Thomsen, P. H. (2020). Group Based Cognitive Behavioural Therapy for Anxiety in Children with Autism Spectrum Disorder: A Randomised Controlled Trial in a General Child Psychiatric Hospital Setting. *Journal of Autism and Developmental Disorders*, 2020-03-26.

Lang, R., Regester, A., Lauderdale, S., Ashbaugh, K., & Haring, A. (2010). Treatment of anxiety in autism spectrum disorders using cognitive behaviour therapy: A systematic review. *Developmental Neurorehabilitation*. https://doi.org/10.3109/17518420903236288

Langdon, P. E., Murphy, G. H., Wilson, E., Shepstone, L., Fowler, D., Heavens, D., Russell, A. (2013). Asperger syndrome and anxiety disorders (PAsSA) treatment trial: A study

protocol of a pilot, multicentre, single-blind, randomised crossover trial of group cognitive behavioural therapy. *BMJ Open*, *3*(7). https://doi.org/10.1136/bmjopen2013003449

Lever, A. G. and Geurts H. M. (2016) Psychiatric co-occurring symptoms and disorders in young, middle-aged, and older adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 46*(6): 1916–1930.

Luchini, C., Stubbs, B., Solmi, M. and Veronese, M. (2017). Assessing the quality of studies in meta-analyses: Advantages and limitations of the Newcastle Ottawa Scale, *World Journal of Meta-Analysis, 5*(4), 80-84.

Luxford, S., Hadwin, J. A. & Kovshoff, H. (2017). Evaluating the Effectiveness of a School Based Cognitive Behavioural Therapy Intervention for Anxiety in Adolescents Diagnosed with Autism Spectrum Disorder. *J Autism Dev Disord 47*(12): 3896-3908.

Maskey, M., McConachie, H., Rodgers, J., Grahame, V., Maxwell, J., Tavernor, L. & Parr, J. R. (2019). An intervention for fears and phobias in young people with autism spectrum disorders using flat screen computer-delivered virtual reality and cognitive behaviour therapy. *Research in Autism Spectrum Disorders 59,* 58-67.

Mefford, H. C., Batshaw. M. L., and Hoffman, E. P. (2012). Genomics, intellectual disability, and autism. *N Engl J Med, 366,* 733–743.

Mignogna, J., Martin, L.A., Harik, J. *et al.* "I had to somehow still be flexible": exploring adaptations during implementation of brief cognitive behavioral therapy in primary care. *Implementation Sci***13,** 76 (2018). https://doi.org/10.1186/s13012-018-0768-z

Moskowitz, L. J., Walsh, C. E., Mulder, E., McLaughlin, D. M., Hajcak, G., Carr, E. G. & Zarcone, J. R. (2017). Intervention for anxiety and problem behavior in children with autism

spectrum disorder and intellectual disability. J*ournal of Autism and Developmental Disorders, 47*(12), 3930-3948.

Murphy, S. M., Chowdhury, U., White, S. W., Reynolds, L., Donald, L., Gahan, H., Iqbal, Z., Kulkarni, M., Scrivener, L., Shaker-Naeeni, H. & Press, D. A. (2017). Cognitive Behaviour Therapy Versus a Counselling Intervention for Anxiety in Young People with High-Functioning Autism Spectrum Disorders: A Pilot Randomised Controlled Trial. *J Autism Dev Disord 47*(11), 3446-3457.

Muskett, A., Radtke, S. & Ollendick, T. H. (2020). Brief, Intensive, and Concentrated Treatment of Specific Phobia in a Child With Minimally Verbal Autism Spectrum Disorder. *Clinical Case Studies 19*(1), 3-16.

Newschaffer, C. J.,, Croen, L. A., Daniels, J., Giarelli, E., Grether, J. K., Levy, S. E., Mandell, D.S., Miller, L. A., Pinto-Martin, J., Reaven. J., Reynolds, A. M., Rice, C. E., Schendel, D. and Windham, G. C. (2007). The epidemiology of autism spectrum disorders. *Annu Rev Public Health, 28,* 235-58.

Oerbeck, B., Overgaard, K, R.,, Attwood, T, & Bjaastad, J. F. (2021). "Less stress": A pilot study on a cognitive behavioral treatment program for anxiety in children with autism spectrum disorders. *Scandinavian Journal of Child and Adolescent Psychiatry and Psychology, 9*(1), 30-40.

Ollendick, T., Muskett, A., Radtke, S. R, & Smith, I. (2020). Adaptation of One-Session Treatment for Specific Phobias for Children with Autism Spectrum Disorder Using a Non-concurrent Multiple Baseline Design: A Preliminary Investigation. *Journal of Autism and Developmental Disorders, 51*(4), 1015-1027.

Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M., ... & Duffy, S. (2006). Guidance on the conduct of narrative synthesis in systematic reviews. *A product from the ESRC methods programme Version*, *1*, b92.

Paulus, J.K., Dahabreh, I.J., Balk, E.M., Avendano, E.E., Lau, J. & Ip, S. (2014). Opportunities and challenges in using studies without a control group in comparative effectiveness reviews. *Research Synthesis Methods, 5*(2), 152-161.

Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008). Psychiatric disorders in children with autism spectrum disorders: Prevalence, comorbidity, and associated factors in a population-derived sample. *Journal of the American Academy of Child and Adolescent Psychiatry*, *47*(8), 921–929. https://doi.org/10.1097/CHI.0b013e318179964f

Solish, A., Klemencic, N., Ritzema, A., Nolan, V., Pilkington, M., Anagnostou, E & Brian, J. (2020). Effectiveness of a modified group cognitive behavioral therapy program for anxiety in children with ASD delivered in a community context. *Molecular Autism 11*(1), 34, 1-11.

Storch, E. A., Schneider, S. C., Nadai, A. S., Selles, R. R., McBride, N. M., Grebe, S, C., Bergez, K. C., Ramirez, A., Viana, A. G. & Lewin, A. B. (2020). A Pilot Study of Family Based Exposure-Focused Treatment for Youth with Autism Spectrum Disorder and Anxiety. *Child Psychiatry and Human Development 51*(2): 209-219.

Strang, J., Kenworthy, L., Daniolos, P., Case, L., Wills, M. C., Martin, A. and Wallace, G. L. (2012). Depression and anxiety symptoms in children and adolescents with autism spectrum disorders without intellectual disability. *Research in Autism Spectrum Disorders, 6*(1): 406–412.

Walters, S., Loades, M. and Russell A. (2016). A Systematic Review of Effective Modifications to Cognitive Behavioural Therapy for Young People with Autism Spectrum Disorders. *Review Journal of Autism and Developmental Disorders, 3,* 137-153.

Warmen, D. M., Grant, P., Sullivan, K., Caroff, S. and Beck, A. T. (2005). Individual and Group Cognitive-Behavioral Therapy for Psychotic Disorders A Pilot Investigation. *Journal of Psychiatric Practice, 11*(1), 27-34.

Wells, G. A., Shea, B., O'Connell, D., Peterson, J., Welch, V., Losos, M., & Tugwell, P. (2000). The Newcastle-Ottawa Scale (NOS) for assessing the quality of nonrandomised studies in meta-analyses.

Wilkins, J. and Matson, J. L. (2009). A comparison of social skills profiles in intellectually disabled adults with and without ASD.*Behav Modif, 33*(2), *143-55.*

Wistow, R. and Barnes, D. (2009). *A Profile of Child and Adolescent Mental Health Services in England 2007-8. Technical Report.* Durham University, School of Applied Social Sciences, Durham.

Wood, J. J., et al. (2020). "Cognitive behavioral treatments for anxiety in children with autism spectrum disorder: A randomized clinical trial." JAMA Psychiatry 77(5): 474-483.
Baron-Cohen, S. (2001). Theory of mind and autism: A review. In L.M. Glidden (Ed.), *International review of research in mental retardation: Autism* (pp. 169–184). San Diego: Academic.

Oxford Institute of Clinical Psychology Training

Service Improvement Project:

Best practice care for dementia and/or delirium related challenging behaviour: Staff views on the impact of COVID-19 on an acute medical ward

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1 Abstract

Objective: COVID-19 brought many additional challenges for both staff and dementia patients in hospital. It is unclear what the impact may be on provision of care. This study aimed to explore staff's understanding of best practice care for this population, and to understand the impact of COVID-19 on providing this, as well as how it may have impacted incidents of challenging behaviour on the ward. Recommendations were reported.

Method: Staff confidence ratings and incidents of aggression and violence prior to, and during the first wave of the pandemic were reported. Interviews were conducted with seven staff members and analysed using content analysis. A dementia carer consulted on the development of the interview schedule.

Results: Incidents of challenging behaviour reduced during the pandemic. Seven themes were derived from the staff interviews: *Training feedback; change in incidents; managing challenging behaviours; adjusting care; toll on staff; no contact from relatives; and team support.*

Discussion: Staff reported to be largely following the NICE guidelines for supporting dementia patients displaying challenging behaviours. Many of these were unable to be implemented during the pandemic due to additional challenges. Staff discussed what additional support would be needed during this time to enable them to provide best practice care.

Keywords: Dementia, Delirium, COVID-19, healthcare, staff

2 Introduction

Challenging behaviours (CB) are behaviours deemed to be dangerous to individuals or considered antisocial within environments where individuals coexist long-term (Andrews, 2006). This includes agitation, "wandering", and aggression, and can impact psychological factors such as anxiety, depression, hallucinations, and delusions (Finkel et al., 1996) and is reliant on context.

Up to 95% of people living with dementia will experience CB (O'Donnell et al., 2007; Ballard et al., 2001) affecting quality of life for the individual and those caring for them (Osbourne et al., 2010). Although previously, CB in dementia were interpreted purely biologically, it was recognised that this was neither empirically supported (Bird & Moniz-Cook, 2008) nor considered the individual and context (Cheston & Bender, 1999). More recently, behaviours have been understood through the biopsychosocial model as meeting psychological and physical needs, seeking meaning, or coping with the environment and stressors (Downs et al., 2008).

Recognition and management of triggers are key to supporting patients and reducing CB (Moniz-Cook et al., 2001; NICE, 2015). Before considering treatment options, behaviours should be understood using a person-centred approach, considering the individual, what they are communicating, and the impact of their difficulties (NICE, 2015). Failure can result in responses that create further CB (Krishnamoorthy & Anderson, 2011) and impact hospital discharge.

A recent ethnography study conducted large-scale observations of healthcare staff responses to dementia patients within five different acute hospital settings across England and Wales,

interviewing patients and carers regarding their perspectives. High levels of resistance or care refusal were noted, including agitation, removing of medical equipment, and absconding. It was observed that staff were unable to notice or prioritise responding to subtle indicators of CB due to high demands. Responses consisted of restraint using bed rails, bed sheets or tray tables, and walking aids being placed out of reach. Notably these responses also commonly triggered patient anxiety and CB (Featherstone et al., 2019). Furthermore, the National Audit of Dementia Care (Royal College of Psychiatrists, 2011) revealed that as little as 5% of acute hospital staff receive mandatory dementia training and Griffiths et al. (2014) found that ward staff felt they lacked the confidence or skills to work with confused patients.

NHS England (2020) recognised patients with delirium and/or dementia (PD/D) may experience a decrease in wellbeing because of COVID-19, recommending support to maintain safe social contact and activities, have accessible information regarding preventing COVID-19 and utilising non-pharmacological approaches. The changes regarding infection control also had an impact for these patients during the pandemic. For example, CB became more difficult to manage on wards. This may be due to PD/D having limited access to information regarding the pandemic, and/or difficulties retaining this information when it is available (Wang et al., 2020). They may become distressed or confused due to associated factors, such as staff PPE, social distancing measures, and an inability to freely explore their environments. Furthermore, previous interventions may not be possible due to ward restrictions.

A UK hospital observed an older adult male ward with higher numbers of PD/D and rates of incidents of aggression towards others than other wards. The Mental Health Liaison Team (MHLT) held training for Health Care Assistants (HCAs) as part of a Quality Improvement (QI) project. This training held before the COVID-19 outbreak in the UK, included behaviour

monitoring and environmental management of CB. During the pandemic, it was clear that some guidance would not be possible due to new infection prevention measures, and that other major changes in the hospital due to the pandemic may have impacted care.

NICE guidance for managing violence and aggression in health settings (NICE, 2015) outlines good practice for managing CB. COVID-19 restrictions likely impacted the ability to meet these guidelines on the ward. As older adults are at higher risk of contracting and being more seriously affected, safeguards from risk of infection during hospital admissions and continuation of adequate care are vital.

This study aimed to evaluate the impact of COVID-19 on older adult dementia care on a ward where CB incidents are high in comparison to other older adult wards. Specifically, the study aimed to explore management of CB associated with PD/D, relative to the NICE guidance for managing violence and aggression in health settings (NICE, 2015), and potential improvements. The following research questions were explored:

1. *What was staff's experience of the previous February 2020 MHLT training; how has this impacted the care they provide since, if at all?*
2. *Have incidents of challenging behaviours risen during the COVID-19 pandemic (from September 2019 – February 2020 to March 2020 – August 2020)*
3. *What do staff consider to be good practice for the management of behaviours related to PD/D)?*
4. *What are the staff's views on the impact of COVID-19 on their ability to confidently support PD/D?*

5. *What are the staff's views on what would be helpful to deliver best practice management of behaviours related to PD/D during the COVID-19 pandemic, applicable to other outbreaks of infectious disease?*

3 Method

3.1. Setting

The study took place on a 28-bedded older adult male acute medical ward, with a high proportion of PD/D admissions. The ward is run by a multidisciplinary team of Nurses, Doctors, HCAs, Physiotherapists and Occupational Therapists.

This study was developed in collaboration between the MHLT, the Dementia Nurse (DN) and Ward Manager.

3.2. Participants

All HCAs (n=16) and Nurses (n=13) working on the ward during the pandemic (i.e. from March 2020) were invited to participate. No exclusion criteria were applied to capture the views of individuals with a range of experiences.

Posters stationed within ward communal staff areas invited staff to participate. Individuals could also volunteer to participate when approached by their ward matron or the researcher. Seven participated (see table one).

Table 1:

Participant experience

Participant	Role	Years in role	Years experience working with dementia
A	HCA	6	6
B	HCA	6	6
C	HCA	1	10
D	Nurse	7	7
E	Nurse	13	10
F	HCA	11	9
G	Ward Sister	16	10

3.3. Measures

3.3.1. Development of the interview schedule

Interview aims and questions were discussed and agreed in collaboration with the Clinical Psychologist specialising in Older Adults within the MHLT, the DN and an expert by experience (see section 3.4.1).

NICE guidelines for managing violent and aggressive behaviour in health settings (NICE, 2015) provided a benchmark for good practice. These are the most comprehensive guidelines for managing CB used by geriatric services. Additional literature on the impact of COVID-19 on hospital care for people with dementia (RCPsych, 2020) was reviewed to provide context for the interviews.

3.3.2. Staff confidence

A questionnaire was developed exploring staff confidence working with PD/D and CB (see appendix F). Participants rated their confidence at the time of the interview and before COVID-19 retrospectively on a 10-point Likert scale.

3.4. Procedure

The project was approved by the Trust's QI director under the QI framework and registered on the NHS-wide database, Life QI.

3.4.1. Patient and public involvement

A service-user perspective supported the development of project aims and interview schedules. This individual cared for a relative with dementia and CB who had experienced hospital care before and during the pandemic.

The carer attended a telephone interview where aims of the project, their experience of hospital care, and what felt important to them was discussed (see appendix G). Based on this, the interview schedule was developed in collaboration with the MHLT and DN. The carer reviewed the final interview schedule and received a monetary voucher for their contribution.

3.4.2. Incidents

Incidents of violence and aggression on the ward were gathered from the Datix system and compared to number of PD/D on the ward.

3.5. Data collection

Participants reviewed the information sheet and provided written consent to participate and for audio recording. Due to unpredictable ward demands, interviews were completed in the ward day-room to minimise disruption. Interviews lasted an average of 32 minutes (23-49mins). Following the interview, participants completed the confidence rating form.

3.6. Data analysis

Interviews were transcribed and coded using the software, NVivo. Content analysis (Stemler, 2000) was employed using four stages: decontextualisation, recontextualisation, categorisation and compilation, using a latent analysis (Bengtsson, 2016). The researcher familiarised herself with the data and each identified meaning unit was labelled with a code. Codes were created inductively. The coded transcribed interviews were then revisited. Meaning units were condensed and divided into categories. Codes and categories were discussed with the research supervisor to ensure reliability.

Categories were matched to existing NICE guidelines for managing violence and aggression within health care settings (NICE, 2015).

4 Results

The content analysis produced seven overarching categories (see appendix H). Each category and subcategory are described within the relevant research question, supported by verbatim excerpts and additional quantitative data.

4.1 RQ1: What was staff experience of the previous training, how has this impacted the care they provide?

4.1.1. Category: MHLT Training

Two interviewees attended the MHLT training and an additional two were aware of the training.

4.1.1.1. Content of the training:

Those who attended appeared satisfied with the training, reporting increased understanding of patient behaviour and helpful ways of responding.

"It was very good to team build to actually understand all together what it means for patients that were very challenging… We were getting very frustrated but once we'd gone through the dementia training we were 'OK, so there's a reason behind that challenging behaviour'"[B]

However, one colleague reported that staff did not "*take from it what they should"[D]*.

4.1.1.2. Implementing learning throughout the pandemic

Although not all agreed, three felt the learning was hard to implement during COVID-19.

"We knew we had more knowledge but might not have been able to take forward everything at that time, so our knowledge was there but our appreciation of other areas that we covered probably you know, took a back step"[B].

4.2. RQ2: Have incidents of challenging behaviours risen during the COVID-19 pandemic?

4.2.1. Quantitative data:

Since the beginning of COVID-19, 50% fewer incidents of 'violence and aggression' were reported via Datix, compared to six months prior (see figure one).

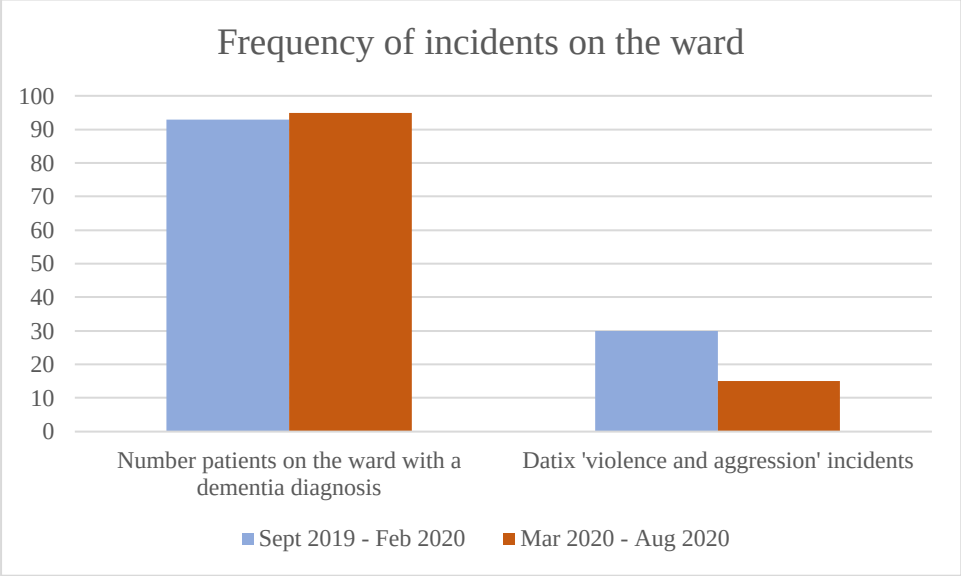

Figure. one: Number of violence and aggressive incidents recorded involving PD/D in relation to hospital admissions prior to and during the pandemic

4.2.2. Category: Change in CB incidents

4.2.2.1. Frequency of incidents

Participants agreed incidents of CB had not increased during the first wave of the pandemic. Two felt there had been no change, and five reported a reduction due to *"less admissions"[E].*

4.2.2.2. Type of incidents

Most felt the types of incidents were no different to pre-covid, although some disagreed with this (n=2).

"The [patients] we did have, did get a little bit worse, they did become a little bit more aggressive, they couldn't understand why we were wearing a mask"[F].

"They get more frustrated because they can't see their loved ones… They get a bit more shouty but it's not as physical"[D].

4.3. RQ3: What do staff consider to be good practice for the management of behaviours related to PD/D?

4.3.1. Category: Managing Challenging Behaviours

Staff were asked what they considered good dementia care for patients with CB.

4.3.1.1. Understanding the individual

The majority of participants (n=6) felt *"individualised care"[G]* was needed, as *"if you understand the patient you are dealing with, you know how to tackle the situation"[C].*

4.3.1.2. Responding to cause of behaviour

Participants reported the need to *"learn and study the person to understand what is happening"[C],* to *"find out what the problem is*"*[D]* and respond to that need, *"if it's something I can fix then I try my best to facilitate it…and that usually calms them down"[D].*

4.3.1.3. Social stimulation

A theme within the interviews was having space for social stimulation on the ward.

Time and support for patients

Many (n=6) reported *"sometimes [staff] need to spend more time with [patients]",* however, *"…our managers say we have no time…Sometimes if we just sit and listen to them that can make a big difference"[E].*

Social activities and stimulation

Staff recognised *"there is not much you can do as a patient on the ward"[A]* and this was impacting their mental health: *"We often see their mental health gets worse because they can't see their family, they can't go out for a walk…they can't do activities like cooking, cleaning, anything that was occupying their mind before, because obviously activities in the hospitals are very limited"[A].* Some felt *"dementia patients end up just being shoved into their bays"[B],* particularly during the pandemic, and many agreed *"we could do with activities to stimulate, and once COVID is over, for families to be able to go in and integrate in the room too"[B].*

Enlisting additional support

Staff stated they apply additional methods to de-escalate CB on the wards if needed. These include enlisting security, "*putting patients on DOLs legal frameworks" [E],* or through medication, ***"****always as the last resort" [C].*

4.3.2. NICE Guidance

Content analysis categories were benchmarked against the guidance for managing violence and aggression within health care settings (NICE, 2015) (see table three).

Table three:

Number of participants who discussed elements of the NICE Guidelines for managing violent and aggressive behaviour (2015).

Guidance	Number of participants	Category
Staff training in psychosocial methods	6	Category: Training and guidance
Restrictive intervention reduction programme	0	
Staff work as a therapeutic team, maintaining staff emotion regulation and self-management, and encourage good leadership	7	Category: Team Support Subcategory: Supporting one another / Support from senior management
Patient offered appropriate psychological therapies and support for communication difficulties	0	
Patient offered appropriate physical activities and leisure activities	5	Category: Managing CB Subcategory: Social Stimulation
Recognise potential bullying/unwanted contact or conflicts between patients	1	Category: Managing CB Subcategory: Understanding the individual
Use knowledge of the individual (assessment of behaviours, triggers and factors involved) to consider how might impact CB (e.g. diagnosis, current symptoms, past history) as well as the impact of being in a restricted environment, restricting a person's liberty and freedom of movement	7	Category: Managing CB Subcategory: Understanding the individual
Address physical environmental factors.	0	

Understand and manage any personal factors outside of hospital that may impact behaviour (e.g. family difficulties, financial worries etc.)	5	Category: No relative contact Subcategory: Impact on patient health Category: Managing CB Subcategory: Social stimulation
Set out prevention strategies to improve QoL, meet needs, and support emotions/symptoms leading to CB.	4	Category: Managing CB Subcategory: Responding to cause of behaviour
Staff to be trained in de-escalation techniques: recognising signs, understanding causes, use techniques for distraction, calming, and encouraging relaxation, responding in measured way	6	Category: Training and guidance
Use outcome measures as well as unstructured clinical judgement to monitor and reduce incidents (including risk assessment).	0	
PRN medication – with a clear rationale and circumstances to be used, not to be given indiscriminately/routinely	5	Category: Managing CB Subcategory: Enlisting additional support
Staff to establish close working relationships with patients at the earliest opportunity and sensitively monitor changes	7	Category: No relative contact Subcategory: Building relationships with the patient
Use range of verbal and non-verbal skills and interactional techniques to avoid or manage 'flashpoint situations'	5	Category: Managing CB Subcategory: Responding to cause of behaviour / Understanding the individual
Explore triggers and early warning signs with patients where possible and negotiate their wishes should they become agitated	5	Category: Managing CB Subcategory: Responding to cause of behaviour / Understanding the individual

Whilst most NICE guidance was discussed, certain guidance was not mentioned highlighting potential gaps in knowledge.

4.4. RQ4: What are the staff's views about the impact of COVID-19 on their ability to confidently support patients with dementia?

4.4.1. Confidence ratings

Participants rated their confidence in supporting PD/D displaying CB prior to COVID-19 and during the first wave.

The mean confidence score was seven out of ten at both time points. There was variation across participants, with a range of three to ten potentially reflecting different levels of training/experience. Across the four domains (see figure two; table four) mean change across time ranged between zero and two. The majority decreased in confidence during the pandemic, although one participant had a one-point increase in confidence working with PD/D and CB over time.

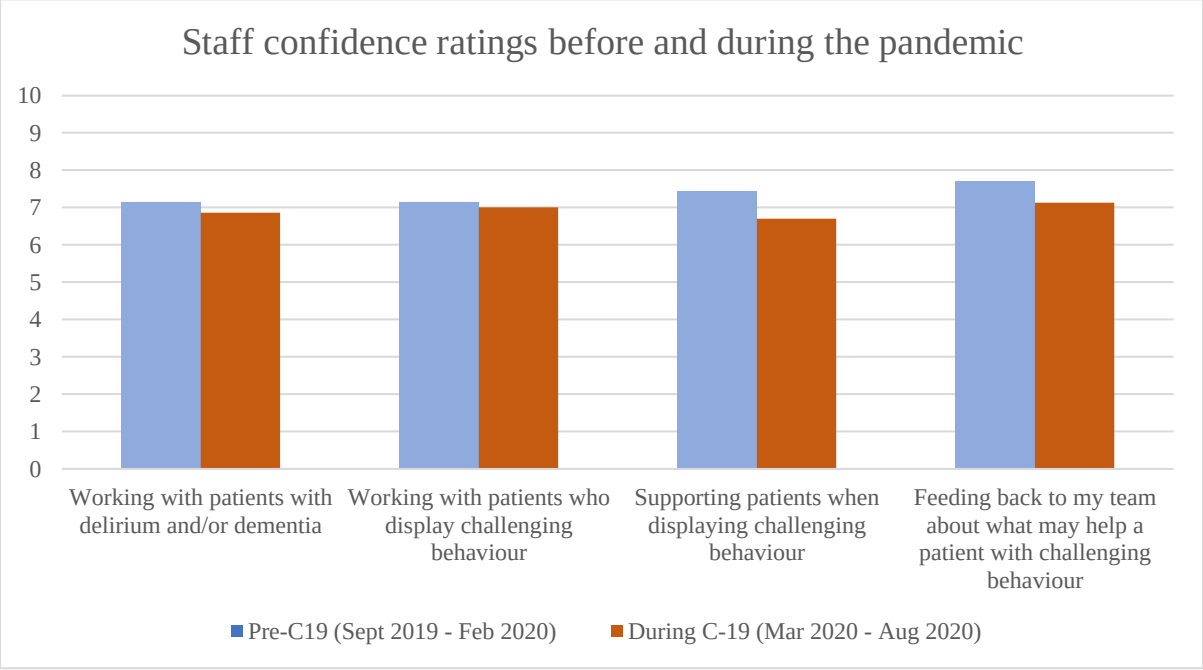

Figure two.: Average staff confidence ratings 6m prior to and during the pandemic

Table four:

Individual staff confidence scores

	Confidence scores pertaining to four domains of working with dementia (confidence scores rated 0-10)							
	Working with PD/D		Working with patients who display CB		Supporting patients when displaying CB		Feeding back to my team about what may help a patient with CB	
	Pre	Post	Pre	Post	Pre	Post	Pre	Post
Participant A	8	8	7	7	7	6	9	8
Participant B	7	5	7	6	7	6	8	7
Participant C	3	4	5	6	6	5	6	6
Participant D	8	8	8	8	8	8	8	7
Participant E	9	9	9	9	9	9	9	9
Participant F	5	4	5	4	5	3	4	3
Participant G	10	10	9	9	10	10	10	10

4.4.2. Category: Adjusting care

Participants described ways COVID-19 impacted care provided for PD/D.

4.4.2.1. Helping patients to understand COVID-19

A key element of working with PD/D was supporting their understanding of the pandemic and new ways of working. *"It was very hard to explain what is happening in the world now, what are the symptoms, and that we can't remove our mask" [A].*

4.4.2.2. Conflict between caring for PD/D, and COVID-positive patients

Responding differently

Providing general care for patients was particularly challenging as guidance for supporting a patient with COVID-19 differed to supporting a patient displaying CB.

Social distancing

Staff commented *"COVID hasn't really impacted the ward"* as *"we can't be two metres apart, it is not possible to be with your patients to closely support them"[B].* Despite this,

staff noted the challenge of not being able to *"spend as much time with them"* and consequently *"you didn't get to know [patients] on a personal level"[F]*.

Maintaining social distancing was also a challenge. *"We had a red zone with [COVID-19] positive patients, we don't want the 'wanderers' to go in there, so we kept one trained and one HCA to concentrate on them"[G]*. This was also managed through *"leaving a couple of bays empty"* for patients who are *"confused, want to walk, and are [COVID-19] positive"[E]*.

Dividing attention

Staff commented on increased pressure during the pandemic caring for PD/D. The urgency of care for COVID reportedly divided their attention: *"We didn't really pay much attention to the rest of the ward at that time, because we were so busy with the COVID patients"[B]*.

Staff reported an overwhelming number of calls from relatives also contributed: *"it actually took us away from giving care to the patients"[D]*.

4.4.2.3. Providing care beyond the essentials

The staff commented that due to *"time and staffing constraints"[B], "workload"[G] and "everything having to be done at a distance"[G]*, they *"can't spend more time with [patients]"[G]*. Staff reported even prior to COVID-19, they were *"not able to put as much effort into particular patients as we would like"[B]* as certain elements of support *"talking, going for a walk with them"[A],"brushing their hair, washing teeth, shaving are luxuries"[B]* and *"sometimes it is hard to provide it"[A]*.

4.4.3. Category: Toll on staff

A key theme was the toll on staff, both working with CB and working during the pandemic.

4.4.3.1. Emotional toll on staff

Staff reported *"fear of being assaulted"[D]* as many had already experienced. Additional fears for safety emerged working with COVID-19 positive patients: *"I'm so scared honestly, I know I will get it… I feel like we are going to a big war without any weapons,,. Just in the front line, just ready to get it"[E]*.

Additionally, some reported taking worries home and "*fear that 'what could I have done to make it better?'"[C]*.

4.4.3.2. Impossible workload

Staff reported the workload is *"impossible to achieve*"*[D]* and therefore elements of care cannot be achieved, *"people don't do things because we haven't got time"[D]*.

4.4.3.3. Staff morale

Relatively, staff felt their worries and concerns were not considered, leading to *"staff morale [being] a big issue"[F]*. One discussed this in relation to concerns working with COVID-positive patients: *"when you try and say something you're told you've just got to get on with it, but it doesn't help you mentally…. You need people that understand that we've got families"[F]*.

4.4.4. Category: No contact from relatives

Many participants noted the impact no visitors had on staff and patients.

4.4.4.1. Building relationships with the patient

Although one felt the lack of relative contact did not impact relationships with patients, five others felt this had an impact on care, particularly as some patients were unable to express preferences and needs:

"how you approach or look after a dementia patient, sometimes you are better judged by having met the family members, or seeing family members with them, seeing what it is that makes them suddenly talk, suddenly smile…those sort of things are missed"[B].

4.4.4.2. Boundaries moved

With the lack of family support for patients, staff reported *"becoming closer to patients"* and *"creating a family atmosphere"[G]* in order to fulfil that role. Staff explained they had *"broken those boundaries a bit because it is only them and us"[G]*. This included information sharing with relatives – *"we are only allowed to give basic information, but you can see that the relatives are expecting more through the phone and sometimes we have to kick that boundary line a little bit further"[E].*

4.4.4.3. Impact on patient health

Many staff (n=4) agreed lack of relative contact had a *"detrimental impact"* on patients, in many ways. Patients became "*really distressed by the fact they can't go and see their loved one*", *("the violence got worse because we couldn't facilitate what they wanted"*) and experienced negative impacts on health, *"when people were going back home they were obviously having bigger deliriums because they weren't seeing family – then they were bouncing back in"[D].*

Although staff were given a device to facilitate video-calls, a lack of training meant it went unused, *"I don't think anyone has used it…I wouldn't even know how to use it, we didn't get training on it"[B]*.

4.5. RQ5: What are the staff's views on what would be helpful to deliver best practice management of behaviours related to delirium and dementia during the COVID-19 pandemic, applicable to other outbreaks of infectious disease?

Staff commented on how they could implement the best practice care they outlined (see RQ3). These have been linked to specific NICE guidance.

4.5.1. Recommendation: Team Support

Guideline: staff working as a therapeutic team, good leadership

Although participants felt supported within their teams, some (n=4) felt they needed more support from seniors.

There was a sense among staff that **"***we support each other"[E]*, "*if I'm having…a hard time I could speak to my manager…and in the team we always talk to each other[A]*. However at a senior level, some felt *"we need more support, we shouldn't be left in situations, at the end of the day it's not what we are here for"[F]*. This included both practical (e.g. during incidents of CB:*"I don't think we get a great deal of support from senior management, a lot of the time they will turn up and then just they'll disappear and security are quite often just left"[D]*) and emotional support ("*in terms of emotional support, there isn't much"[A]*). Two however disagreed and felt "*senior management have been very supportive"[G]* during COVID-19.

4.5.2. Recommendation: Training and guidance

Guideline: Staff training

4.5.2.1. Benefit of training

All participants felt *"additional training is never a bad idea. You can always learn something, and every patient is specific on their own"[A]*. It was felt all staff should attend to have a consistent understanding of each patient.

4.5.2.2. Written accessible guidance

Due to the unfamiliarity of COVID-19, five felt "*we need a protocol in place"[E]* for certain eventualities. However, one felt policies were inaccessible on busy wards *"if you want to find a policy on the intranet you have to be prepared to give up three days of your life to find it"[D]*. One individual suggested accessible guidance such as *"a support guide or tool kit to give that, if you don't know what to do, what is the next step"[D]* for support around managing CB on the ward. Four said they were unaware of any existing guidance.

4.5.3. Recommendation: Social stimulation

4.5.3.1. Relative contact

Guideline: Improve QoL; Meet their needs

Due to the impact of reduced visitation, staff were keen for this to change. *"If I could change anything I would want visiting – I would insist that they made a ruling for wards like ours that we could have visitors in because for me that's what caused the biggest detriment to these people"[D]*.

4.4.3.2. Stimulating activities

Guideline: Encourage meaningful activities

Staff also expressed *"the biggest problem we've got is there is nothing for them to do"[D]*, often resulting in CB. Although several activities could not continue during the pandemic, staff felt safe activities could be introduced.

4.4.3.3. Resources

Guidelines: Dedicated time to engage positively with patients; Establish close working relationships

It was clear that staff felt they needed *"time [and] more staffing"[B]*. Staff noted during the pandemic it was challenging managing CB *"to be able to not just manage that situation, but also manage other patients who understand COVID, keep them calm [and] keep your staff calm"[B]*. Having additional support "*takes the pressure off everyone else. It just makes it safer"[F]*.

Two expressed hopelessness regarding change– *"it's always going to be the same, it's going to be staffing and it's going to be time and I just don't think either of those are achievable, sadly"[B]*.

5. Feedback to the service

Results were disseminated with recommendations to senior management and the dementia steering group via an oral presentation, a written summary and posters outlining the key recommendations and best practice guidance (see appendices K-M).

6. Discussion

COVID-19 clearly impacted care delivered to PD/D displaying CB. The pandemic saw a reduction in violence and aggression on the ward, despite admissions remaining relatively stable. This could be due to the nature of the admissions with more severely unwell patients occupying the majority of beds, or due to infection restrictions.

Despite several (n=4) members of staff being unaware of written guidance for managing CB, they highlighted several of the guidelines as best practice, such as understanding behaviour within the context of the individual and responding to the cause or unmet needs. Staff also maintained that medication should be a last resort in line with NICE guidance (NICE, 2015). Certain elements of what staff considered best practice were not possible during the pandemic. A lack of time and resources impacted staff ability to spend time learning about, assessing, and monitoring individual patients, potentially resulting in missed opportunities for prevention. Staff lacking capacity to develop relationships, understand the patient (Krishnamoorthy & Anderson, 2011) and recognise warning signs for incidents leads to further anxiety and CB (Featherstone et al., 2019; Moniz-Cook, Woods & Richards, 2001). Although staff showed an awareness of the impact of restricted environments and lack of stimulating activities, due to COVID-19 restrictions these could not be rectified. With high levels of staff anxiety, there appeared to be lack of emotional containment for staff, which may have contributed to staff feeling more guidance and emotional support was needed.

Some NICE guidance for managing CB was not discussed by staff. Within the hospital, the MHLT supports wards with assessment and CB management strategies, however staff did not indicate utilising them for psychological or communication guidance for patients. Similarly, guidance suggests the use of outcome measures to support assessment of CB, a restrictive intervention reduction programme, and consideration of environmental factors (NICE, 2015). Staff did not highlight these during discussions, and therefore it is possible they are not aware of these factors that could improve patient care and reduce CB.

Implication for supporting PD/D during COVID-19 and/or other infectious disease outbreaks

Considering the results in conjunction with the NICE guidelines, staff may be unaware of factors supporting the prevention and de-escalation of CB within and outside of COVID-19. It is therefore imperative that staff receive appropriate knowledge through training and accessible written guidance.

Staff appeared to be aware of the majority of NICE guidelines for managing CB, however it was clear this was more challenging to implement during the pandemic. We, therefore, recommend the ward considers adapted activities to increase stimulation, sense of purpose, and subsequently QoL. This should include engaging positively with patients and supporting use of technology to connect with relatives. Staffing should be reviewed to ensure there are sufficient resources to appropriately assess, observe and monitor patients, and training should be provided for outcome measures and consulting with the MHLT to ensure patients who may benefit from psychological support have equal access.

To improve staff wellbeing and support, the ward should collaborate with staff to agree a plan for providing emotional support. This could be in the form of reflective spaces held by management or external figures such as the MHLT.

Impact on practice

As a result of the recommendations, the MHLT is holding additional training to support understanding of CB, and develop skills in assessment, prevention, and de-escalation techniques. Seniors aim to stress the importance of increasing patient wellbeing during every encounter, rather than waiting for additional opportunities.

Posters outlining best practice care have been made available on the ward in an accessible format for staff (see Appendix L, M). In addition, the dementia steering group will employ a Meaningful Activities Coordinator to support activities on the ward and consider additional methods such as use of an iPad to show videos, a text service to keep in touch with relatives, and dancing/singing opportunities.

Limitations and Further study

This study allowed staff voices to be heard regarding what support is needed during the pandemic to support dementia patients. As the pandemic could not be predicted, some of the pre-COVID quantitative data such as confidence ratings were completed in retrospect, and therefore may have been subject to bias. Additionally, although the most accurate method of capturing the frequency of CB incidents was via the Datix, due to the ways these were recorded, these were only reflective of incidents of aggression and violence, and therefore may not be an accurate representation of CB more widely.

Conducting interviews in staff's place of work may also have impacted how open they felt able to be, however this method of data collection was deemed to be the least disruptive to the busy service. Additionally, content analysis categories were benchmarked against NICE guidance, however asking staff directly about different elements of the NICE guidance may have better represented care delivered during the pandemic.

A full report of the outcome of the research and recommendations were submitted to senior management. MHLT will continue to monitor the impact of the implemented changes outlined on the incidents of CB on the ward. It may be useful to continue to monitor staff confidence and explore patient/carer experience of care to further develop quality of care.

References

Andrews, G. (2006). Managing challenging behaviour in dementia. *BMJ, 332*(7544), 741.

Bird, M., & Moniz-Cook, E. (2008). Challenging behaviour in dementia: A psychosocial approach to intervention. In R. Woods & L. Clare (Eds.), *Handbook of the Clinical Psychology of Aging* (pp. 549–571). West Sussex: John Wiley and Sons Ltd.

Ballard, C., O'Brien, J., James, I. & Swann, A. (2001). *Dementia: Management of behavioural and psychological symptoms.* Oxford: Oxford University Press.

Bentsson, M. (2016). How to plan and perform a qualitative study using content analysis. N*ursingPlus Open, 2,* 8-14. https://doi.org/10.1016/j.npls.2016.01.001.

Cheston, R., & Bender, M. (1999). *Understanding dementia: The man with the worried eyes*. London: Jessica Kingsley Publishers Ltd.

Downs, M., Clare, L., & Anderson, E. (2008). Dementia as a biopsychosocial condition: Implications for practice and research. In R. Woods & L. Clare (Eds.), *Handbook of the clinical psychology of ageing* (pp. 549–571). West Sussex: John Wiley and Sons Ltd.

Featherstone, K., Northcott, A., & Bridges, J. (2019). Routines of resistance: an ethnography of the care of people living with dementia in acute hospital wards and its consequences. *International Journal of Nursing Studies, 96,* 53-60.

Finkel, S.I., Coste e Silva, J., Cohen, G., Miller, S., & Sartorius, N. (1996). Behavioral and psychological signs and symptoms of dementia: A consensus statement on current knowledge and implications for research and treatment. *International Psychogeriatrics, 8*, 497–500.

Griffiths, A., Knight, A., Harwood, R., & Gladman, J. R. (2014). Preparation to care for confused older patients in general hospitals: a study of UK health professionals. *Age and ageing*, *43*(4), 521-527.

James, I. A., & Moniz-Cook, E. (2018). Evidence briefing: behaviour that challenges in dementia.

Krishnamoorthy, A., & Anderson, D. (2011). Managing challenging behaviour in older adults with dementia. *Progress in Neurology and Psychiatry, 15*(3), 20-26.

NICE. (2019). *Delirium: prevention, diagnosis and management.* (Clinical guideline [CG103]). Retrieved from https://www.nice.org.uk/guidance/cg103/chapter/1-Guidance#treating-delirium

Moniz-Cook, E, Woods, R. T. & Richards, K. (2001). Functional analysis of challenging behaviour in dementia: the role of superstition. *Intf Geriatr Psychiatry,16*, 45-56.

National Institute for Health and Care Excellence. (2015). Violence and aggression: short-term management in mental health, health and community settings. [NICE Guideline No. NG10]. https://www.nice.org.uk/guidance/ng10.

National Institute for Health and Care Excellence. (2015b). Antipsychotics in people living with dementia. [NICE Guideline No. KTT7]. https://www.nice.org.uk/advice/ktt7/chapter/Evidence-context

NHS England. (2020). *Dementia wellbeing in the COVID-19 pandemic*. NHS England.

O'Donnell, M. J., Lewis, D. L., Dubois, S., Standish, T.I., Bedard, M., and Molloy, D.W. (2007). Behavioural and psychological symptoms in community-dwelling elderly persons with cognitive impairment and dementia: Prevalence and factor analysis. *Clinical Gerontologist, 30*, 41–52.

Osborne, H., Simpson, J., & Stokes, G. (2010). The relationship between pre-morbid personality and challenging behaviour in people with dementia: A systematic review. *Aging & Mental Health, 14*(5), 503-515.

Royal College of Psychiatrists (2011). Report of the National Audit of Dementia Care in General Hospitals. Editors: Young J, Hood C, Woolley R, Gandesha A and Souza R. London: Healthcare Quality Improvement Partnership.

Royal College of Psychiatrists. (2020). *COVID-19: Working with vulnerable people.* Retrieved from: https://www.rcpsych.ac.uk/about-us/responding-to-covid-19/responding-to-covid-19-guidance-for-clinicians/community-and-inpatient-services/covid-19-working-with-vulnerable-patients

Stemler, S. (2000). An overview of content analysis. *Practical assessment, research, and evaluation, 7*(1), 17.

Wang, H., Li, T., Barbarino, P., Gauthier, S., Brodaty, H., Molinuevo, J. L., ... & Yu, X. (2020). Dementia care during COVID-19. *The Lancet, 395*(10231), 1190-1191.

Oxford Institute of Clinical Psychology Training

Theory Driven Research Project:

The Development of an Adolescent Sensory Coping Measure

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(Oxford Health NHS Foundation Trust)

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All supervisors have read and provided feedback on this work and deemed it suitable to submit for assessment

1. Abstract

Background: Autism and trauma responses have significant diagnostic overlap, which can lead to misdiagnosis and delayed or inappropriate intervention. Research suggests that sensory modulation may differ in autism and trauma. However, there are no adolescent self-report measures available that explore sensory modulation in detail.

Objectives: The current study aimed to (a) develop a self-report adolescent sensory modulation questionnaire, and (b) explore any differences in the ways autistic young people, and young people who have experienced an adverse life event, modulate their sensory experiences.

Method: Questionnaire items were developed through literature searches and consultation with experts (n=7) and young people with sensory sensitivities (n=9). 507 young people completed the questionnaire, and an exploratory factor analysis was conducted to reveal the final subscales.

Results: Exploratory Factor Analysis discovered three subscales within the measure; sensory-seeking, withdrawal, and interpersonal strategies. The measure had good internal consistency and divergent validity. Withdrawal significantly predicted autism scores, whilst withdrawal and sensory-seeking subscales significantly predicted Adverse Childhood Experience scores. Modulation subscales were significantly higher in the autism and trauma groups compared to controls. Withdrawal was approaching significance as higher in the autism group compared to the trauma group.

2 Introduction:

Sensory processing is an important and complex process, involving interpretation and organisation of sensory input to understand experiences (Jorquera-Cabrera et al., 2017) and respond appropriately (Dunn, 1997). Modulation allows individuals to monitor and regulate sensory information to produce an appropriate response (Harrison et al., 2019). Neurological thresholds for the registration of sensory input exist on a continuum, differing across individuals and dependent on environmental factors. As described in Dunn's Model of Sensory Processing (Dunn, 1997), individuals with low neurological thresholds (hypersensitive) may experience sensory input more intensely than others, and subsequently may be more responsive. Conversely, individuals with high neurological thresholds (hyposensitive) may need more input to register this and therefore may be less responsive. Behavioural responses also exist on a continuum between passive (e.g. internal responses such as staying in a noisy environment, feeling uncomfortable) and active (e.g. controlling sensory input through leaving the noisy area) response strategies (Dunn, 1997).

Hypo- and hyper-sensitivities are often associated with autism (Lane et al., 2010) and included as one of its defining features in the Diagnostic and Statistical Manual for Mental Disorders-5 (DSM-5) (American Psychiatric Association, 2013). Sensory related differences are not exclusive to autism however, and are recognised in several clinical presentations, including Attention Deficit and Hyperactivity Disorder (ADHD) (Mangeot et al., 2001), schizophrenia (Olson, 2011), eating disorders (Brand-Gothelf et al., 2016) and trauma response (Engel-Yeger et al., 2013).

Sensory processing differences are one of many shared characteristics of autism and trauma response which can make distinguishing between these challenging. Although it is hypothesised that autistic individuals are more likely to experience traumatic stress compared to their neurotypical peers (Kerns et al., 2015), the impacts of traumatic experiences are frequently missed in this population due to the symptomology overlap (Kildahl et al., 2020). Similarly, trauma responses (e.g. inflexibility, difficulties in social communication and interaction, emotion dysregulation (Moran, 2010)) can mask potential autism. Hoover et al. (2018) found individuals exposed to adverse childhood experiences (ACEs) were more likely to experience a delay in receiving an autism diagnosis, compared to those who had not experienced ACEs.

Furthermore, several studies demonstrated a higher rate of autism diagnosis in young people (YP) who have experienced ACEs. Although the prevalence of autism is 2.27% (Centers for Disease Control and Prevention, 2018), several studies have found much higher rates of autism in YP who have experienced maltreatment and other ACEs (e.g. Green et al., 2016; Melzer et al., 2003; Rutter et al., 1999; Sadi et al., 2012). The symptomology overshadowing across these two presentations results in diagnostic challenges, potential misdiagnoses, and subsequent delayed or ineffective treatments (Stack et al., 2019).

To address the overlap between trauma responses and autism, Moran (2010) developed The Coventry Grid, highlighting similarities and differences between these groups. One area of overlap identified was sensory processing. Moran suggested that both groups may have lower than average thresholds and responses for interoceptive registration (e.g. temperature, pain), although it is unclear whether this was linked to hypo- or hyper-sensitivities. Autistic individuals use more passive strategies (e.g. sitting with discomfort), whilst individuals who

have experienced ACEs use more active strategies (e.g. informing caregivers through strong reactions). Secondly, Moran postulated that self-stimulation was used in both groups, meeting a sensory need for autistic individuals, and displayed through sexualised or self-harming/self-injurious behaviours to seek support, self-soothe, or manage difficult emotions following ACES (Moran, 2010; 2015). The information within the Coventry Grid however is based on anecdotal clinical experiences, limited in detail and evidence.

Despite the body of literature around sensory experiences, research examining sensory modulation in different clinical groups is lacking. Hypersensitivities can be modulated through avoidance, dissociation, food restriction, or hypervigilance, whereas hyposensitivities might be modulated more commonly through sensory-seeking, impulsivity, over-focused attention, or inattention to the environment (Brand-Gothelf et al., 2016; Engel-Yeger et al., 2013; Lane, Young, Baker, & Angley, 2010; Mangeot et al., 2001; Olsen, 2011).

Autistic individuals and those with ACEs share some common ways of modulating sensory sensitivities (e.g. avoidance) (e.g. Ben-Sasson et al., 2008; Brand-Gothelf et al., 2016; Engel-Yeger et al., 2013; Engel-Yeger et al., 2018; Mimouni-Bloch, 2018; Moran, 2015; Olsen, 2011; Sharfi & Rosenbum, 2015), however, there also appears to be some key differences. For example, dissociation is reported most commonly within the trauma literature (e.g. Engel-Yeger, et al., 2013), whereas sensory-seeking is associated more with hyper- and hypo-sensitivities in autism (e.g. Lane et al., 2010).

Although several sensory processing measures currently exist (e.g., Sensory Experiences Questionnaire (Baranek et al., 2006); Sensory Profile (Dunn, 2014)) including some modulation aspects, these focus primarily on sensory experiences. There are currently no

self-report adolescent measures that comprehensively explore cognitive and behavioural modulation strategies in enough detail to explore differences between clinical populations. A sensory modulation measure would allow for the exploration of modulation differences applicable across a range of populations.

Aims and Hypotheses

This study aims to address a gap in assessment tools by developing a measure to aid the identification of sensory modulation strategies.

The following hypotheses (H_x) were explored:

Primary hypotheses:

H_1: Coherent themes and factors will emerge from the data

H_2: The measure will have good internal consistency, convergent validity and divergent validity.

Secondary hypotheses:

H_3: One or more sensory modulation subscales will predict unique variance in autism trait scores, when other relevant variables are taken into account.

H_4: One or more sensory modulation subscales will predict unique variance in ACE scores, when other relevant variables are taken into account.

H_5: Significant differences in sensory modulation scores will be found between "pure" autism, trauma and control groups.

3. Study One: Questionnaire Development

3.1. Method

3.1.1. Participants

3.1.1.1. Experts

Experts working with individuals with sensory sensitivities within specialised neurodevelopmental and trauma Child and Adolescent Mental Health Services (CAMHS) were recruited. No further inclusion/exclusion criteria were applied to capture a range of professionals' views.

Participants were recruited via email advertisements (see appendix O) disseminated by two CAMHS Clinical Leads. Fourteen professionals expressed interest, and seven attended the focus group (Clinical Team Manager; two Occupational Therapists; Cognitive Behavioural Therapist; Mental Health Nurse; Trainee Clinical Psychologist; Research Assistant) (see Table one for participant information).

Table one:

Participant Information: Experts Focus Group

Participant Information		N (%)
Gender	*Male*	0
	Female	7 (100%)
Ethnicity	*White British*	5 (71%)
	Other mixed ethnic background	2 (29%)
Age range	*25-34 years*	3 (43%)
	35-44 years	2 (29%)
	45-54 years	2 (29%)
Team	*Specialist trauma CAMHS**	3 (43%)
	*Specialist Neurodevelopmental CAMHS**	4 (57%)
Years experience**	*< 1 year*	1 (14%)
	1-3 years	1 (14%)
	4-6 years	2 (29%)
	7-9 years	2 (29%)
	>10 years	1 (14%)

**Child and Adolescent Mental Health Service*
***Number of years' experience working with individuals with sensory sensitivities*

3.1.1.2. Young People Consultation

YP aged 13-18 years with sensory sensitivities, and whom had a self-reported diagnosis of autism and/or had experienced an ACE, were recruited via CAMHS and social media to consult on the development of the measure and further guide item selection. Clinicians within seven CAMHS teams shared the online information sheet (see appendices R-T) with eligible individuals on their caseload. An advertisement was also shared on social media (see appendix Y). Interested YP provided written consent (see appendices Z-EE). YP under 16-years provided additional parental consent. Clinicians had no further involvement in recruitment/the research.

Nine YP completed the online survey. The majority were female (N=6), aged 16-18 (N=7), and White British (N=6). All lived in the UK. All self-reported a diagnosis of autism (N=6)

or having experienced a traumatic event (N=3). Additional comorbidities included ADHD (N=2), hearing impairment (N=1), Tourette's syndrome (N=1) and anxiety (N=1).

3.1.2. Procedure

3.1.2.1. Literature review

A literature review of sensory modulation strategies used in the general population and a range of clinical groups was conducted. Search terms (Appendix FF) pertaining to sensory modulation were entered into Web of Science, PsychINFO and Ovid search engines. Titles, abstracts and relevant full-texts were screened by the researcher. Descriptors of sensory modulation strategies from the literature were compiled into an item pool (Appendix GG).

3.1.2.2. Experts Focus Group

Professionals attended a focus group to discuss sensory modulation strategies encountered clinically and feedback on an initial questionnaire draft developed via the literature review. They consulted on the content, structure, layout, and wording. Professionals completed an online demographic survey prior to attending (see appendix HH).

3.1.2.3. Young People Consultation

To increase accessibility of the study, YP could participate via a focus group, individual interview, or online survey. All contributed via online survey using a unique ID.

Participants provided demographic information, their experiences of sensory input, and the modulation strategies they use (see appendix II). They were asked to consult on the items,

wording and accessibility of the questionnaire and suggest further recommendations. Participants were provided £7.50 voucher compensation in line with Trust policy.

3.1.3. Measures

3.1.3.1. Interview/Survey

A semi-structured interview schedule and online survey (see appendices II-JJ) for the above consultations was developed by the research team (EM, CC, MC, JS), including two CAMHS Clinical Leads with expertise in working with YP who are autistic and/or have experienced trauma.

3.2. Outcome of Study One

The consultations resulted in several questionnaire changes. Additional items were added, and wording was adapted to be more accessible to the population group. Additionally, a definition of sensory input was included throughout the questionnaire to support the reader. More frequent breaks in text/items and additional 'free-text' boxes were added for additional information.

The final questionnaire consisted of Part A (sensitivities) and Part B (management strategies). A Likert scale was used to assess frequency of strategy use. Based on the literature and consultations, the questionnaire focused largely on active management strategies.

Professionals commented on the usefulness of the measure for CAMHS settings to facilitate clinicians and families understanding of sensory modulation strategies.

4. Study Two: Questionnaire validation

4.1. Method

4.1.1. Participants

YP aged 13-18 years (N=507) were recruited via social media (Twitter, Instagram, Tiktok, Facebook). This broad inclusion/exclusion criteria hoped to capture a heterogeneous sample representative of the general population, whilst ensuring participants could self-complete the questionnaire and access this through social media.

4.1.2. Procedure

Advertisements were shared via social media. Following consent, participants navigated to the survey, which consisted of demographic information (see appendix OO), existing self-report measures (see section 4.1.3) and the newly developed questionnaire (appendix PP). Participation was anonymous.

4.1.3. Measures

4.1.3.1. Autism-Spectrum Quotient–Adolescent (AQ-Adol) (Baron-Cohen et al., 2006)

This 50-item questionnaire assessing autistic traits in YP has reasonable face validity, internal reliability (α=.79), and excellent test re-test reliability (*r*=.92) (Baron-Cohen et al., 2006). Although this measure was developed as parent-report, the authors consented to and confirmed its suitability to be adapted as a self-report measure for our context (see Appendix RR).

4.1.3.2. Center for Youth Wellness (CYW) Adverse Childhood Experiences Questionnaire (ACE-Q) Teen Self-Report (Burke Harris & Renschler, 2015)

This 19-item self-report measure was adapted from the original ACE study (Fellitti et al., 1998) for use with adolescents (Burke Harris & Renschler, 2015), assessing one's number of ACEs (see appendix SS).

The original ACE questionnaire has good reliability and validity for use with adults (Anda et al., 2010). Although the CYW ACE-Q is not validated, it has been recommended for adolescents (Lee et al., 2018).

4.1.3.3. Sensory Processing Scale Inventory (SPSI) (Schoen et al., 2017)

This 137-item parent-report measure of sensory modulation explores over-responsivity, under-responsivity and sensory-seeking/craving. It has good internal reliability (α=.94), discriminant validity ($p \leq .002$) and construct validity ($p \leq .002$) (Schoen et al., 2017). Authors developed this self-report version for adults/adolescents (Appendix TT) however no psychometrics currently exist.

4.1.4. Determining sample size

Krejcie and Morgan's (1970) formula (MOE=5%; df=1) resulted in a suggested sample of 384. Other guidance suggests 300 is good (Tabachnick & Fidell, 2007), and 500 is a very good (Comrey & Lee, 1992) sample for exploratory factor analysis (EFA).

4.1.5. Ethics and data security

Ethical approval was sought from the University of Oxford Health Research Authority (HRA), through the Integrated Research Application System, and Oxford Health NHS Foundation Trust Research and Development Department (22/EE/0031; amendments NS01; SA1; SA002).

Participants viewed information sheets and provided informed written consent before participation, collected via a GDPR UK compliant online survey tool, Qualtrics, in line with BPS ethics guidelines for online research (British Psychological Society, 2021).

Data were stored securely in line with UK GDPR. Email addresses were retained to provide the monetary reimbursement and then deleted. Identifiable data were kept separate in a secure, password-protected file accessed by the researcher only. All other data were allocated a participant ID and pseudonymised. Data were extracted from Qualtrics and stored securely within an encrypted NHS server. Anonymised data were transferred to the University of Oxford server for analysis. Signposting to further support was included on information sheets and at the end of the questionnaire.

4.1.6. Data Analysis

A total of 1503 visits to the questionnaire were recorded. Of these, 65.1% (n=978) provided consent to participate. Of those who consented, 51.8% (n=507) completed the survey in its entirety (see appendix ZZ).

Data were deemed to have met statistical assumptions prior to analysis. For EFA these included linearity, multicollinearity, and adequate sample size. Although kurtosis and skewness suggested normal distribution, this was not confirmed by Shapiro-Wilk tests and certain histograms, and therefore a principal axis factoring method was used as it is less sensitive to normality violations. As items were expected to correlate, an oblique method of rotation, Promax, was administered. In determining number of factors, a combination of inspecting eigenvalues, scree plots, parallel analysis, and minimal average partial (MAP) analysis was conducted. Factor loadings >.4 were retained to reveal subscales.

Cronbach alpha tests were performed to calculate internal consistency. Spearman rho correlations were used to calculate convergent validity against the SPSI and divergent validity against participant age; a variable expected to have no interaction with sensory modulation. Non-parametric tests were used as the relationship between variables was non-linear.

Multiple regressions were calculated to determine the subscales discriminant validity. Assumptions of sample size, multicollinearity, lack of outliers, linearity and homoscedasticity were met.

To examine group differences, a one-way ANCOVA was performed. Assumptions of normality, linearity, homogeneity of variance and homogeneity of regression slopes were met.

4.2. Results

4.2.1. Descriptive statistics

Sample demographic data are reported in table two.

Table two:

Sample Demographic Data

Demographic		**N (%)**
Gender[2]	*Male*	71 (14.00%)
	Female	257 (50.69%)
	Non-binary/third gender	110 (21.70%)
	Prefer to self-describe:	44 (8.68%)
	Demi-girl / Demi-boy	7 (1.38%)
	Agender	5 (.99%)
	Gender fluid	10 (1.97%)
	Pangender	3 (.59%)
	Transgender	12 (2.37%)
	Fluctuating	2 (.39%)
	Gender queer	1 (0.20%)
	Implagender	1 (0.20%)
	Don't mind	2 (.39%)
	Unsure	1 (0.20%)
	Prefer not to say	25 (4.93%)
Age	*13 years*	126 (24.85%)
	14 years	116 (22.88%)
	15 years	91 (17.95%
	16 years	98 (19.33%)
	17 years	50 (9.86%)
	18 years	26 (5.13%)
		M(SD) = 14.80 (1.49), Median = 15.00
Location	*United Kingdom and Northern Ireland*	412 (81.26%)
	Ireland	79 (15.58%)
	United States of America	6 (1.18%)
	Canada	3 (.59%)
	Germany	1 (.20%)
	Iceland	1 (.20%)
	Italy	1 (.20%)
	Kenya	2 (.39%)
	Mexico	1 (.20%)
	Philippines	1 (.20%)
Ethnicity	*White British*	340 (67.06%)
	White Irish	69 (13.61%)

[2] Categories adapted from UK Census 2021 (gov.uk)

	Other White Background	45 (8.88%)
	Indian	4 (.79%)
	Bangladeshi	2 (.39%)
	Caribbean	4 (.79%)
	Other Asian background	2 (.39%)
	African	4 (.79%)
	Other Black African or Caribbean background	2 (.39%)
	Arab	4 (.79%)
	White and Black Caribbean	4 (.79%)
	White and Black African	3 (.59%)
	White and Asian	5 (.99%)
	Other mixed ethnic background	13 (2.56%)
	Other	6 (1.18%)
Socioeconomic status[3]	*Professional background*	290 (57.20%)
	Intermediate background	95 (18.74%)
	Lower socioeconomic background	87 (17.16%)
	Missing data	35 (6.90%)

Participants self-reported diagnoses that may impact on their sensory experiences (see table three). Although no participants selected 'none', 34 participants did not complete this question.

Table three:

Self-reported diagnoses

Self-reported diagnosis	N (%)
Visual impairment/difficulties with eyesight	151 (29.78%)
Hearing impairment/difficulties with hearing	42 (8.28%)
Autism Spectrum Disorder	180 (35.50%)
Attention Deficit and Hyperactivity Disorder	134 (26.43%)
Sensory Processing Disorder	87 (17.16%)
Mental health difficulties	285 (56.21%)
Experienced a difficult life event/trauma	191 (37.67%)
Other	56 (11.05%)
Unsure	104 (20.51%)
Prefer not to say	12 (2.37%)

[3] Based on highest parental occupation. Occupations scored in line with government guidance (ONS.GOV.UK)

4.2.2. H_1: Coherent themes and factors will emerge from the data

EFA was deemed suitable following data inspection (KMO =.938; Bartlett's test of sphericity *p*=<.001). The correlation matrix determinant was <.00001, however all correlations were <.7 and all diagonal anti-image correlations >.5 (Kaiser & Rice, 1974), therefore no items were excluded from the analysis.

In determining number of factors to extract, Kaiser's criterion of eigenvalues >1 and parallel analysis both over-factored (18 and 65 factors respectively). Scree plots produced between two and four factors. MAP analysis revealed seven factors. Given these findings, two, three and four factors were trialled.

The two-factor solution were too broad to be defined theoretically. Four factor-solution did not produce a reliable result. Three factors were therefore retained. Examining the factor loadings >.4 on each cluster suggested the following factors; 'withdrawal from sensory input', 'sensory seeking' and 'interpersonal strategies' (see table four; appendix AAA).

Table four:

Rotated Factor Loadings for the Final Subscales of the Sensory Modulation Measure.

Item	Withdrawal	Sensory seeking	Inter-personal
I tend to look down rather than at my surroundings	0.77		
I cover my ears	0.73		
I withdraw or move away from others	0.72		
I withdraw from activities where I have to move my body a lot (e.g. sports)	0.70		
I shut down emotionally	0.65		
I move away from what is providing the sensory input	0.62		
I look out for more things that might cause me upset (e.g. things that might make loud noises etc.)	0.58		
I make the same noises over and over	0.58		
I rock my body backwards and forwards or side to side	0.57		
I only go to places I know	0.56		
I am always moving, even when I don't need to		0.67	
I jump and run a lot		0.67	
I move quickly		0.64	
I do activities where I can move my body, like swinging on a swing, swimming		0.64	
I look into the sun or bright lights		0.43	
I go to rooms with lots of noise in (e.g. the kitchen or bathroom rather than bedroom or living room)		0.41	
I look at objects/watch them spin close to my eyes		0.40	
I touch people in a way that they tell me they don't like			0.80
I touch people so hard that they say it hurts them			0.73
People tell me that sometimes I get too close to them			0.73
I hurt others physically			0.60
I often push or play roughly with others			0.60
I crash into the floor or other people/objects on purpose			0.49
I say things that people say are rude or horrible			0.47
I tell others something isn't right by shouting/screaming			0.47
α	*.85*	*.76*	*.86*

A maximum of ten highest loading items >.4 on each factor were retained to create the measure. Items loading >.4 across two factors were removed. A final measure of 25 items was produced (see appendix BBB). There were minimal cross-loadings (see appendix AAA) and factor correlations were below .7 (see table five).

Table five:

Correlations between Factors.

Factor	Withdrawal	Sensory seeking	Interpersonal
Withdrawal	-	.57	.59
Sensory seeking		-	.62
Interpersonal			-

4.2.3. H_2: The measure will have good internal consistency, convergent validity and divergent validity.

Cronbach alpha revealed good internal consistency (George & Mallery, 2003) across all factors (see table four).

Age was significantly but weakly correlated (Dancey & Reidy, 2007) with total score (r_s =-.215, p<.001), sensory seeking (r_s =.250, p<.001) and interpersonal strategies (r_s =.212, p<.001). Age was not significantly correlated with withdrawal (r_s =-.074, p=.097). These results confirm the measure's divergent validity as effect sizes were low (Cohen, 1998).

Regarding convergent validity, no significant correlations between the measure subscales and SPSI subscales (see table six) confirming the null hypothesis.

Table six:

Spearman's Rho Correlation Coefficients between the New Measure and SPSI.

Subscale	Withdrawal	Sensory Seeking	Interpersonal	Total
SPSI* Checklist 1	r_2=-.02 *p*=.32	r_2=-.01 *p*=.41	r_2=-.01. *p*=.45	r_2=-.00 *p*=.47
SPSI* Checklist 2	r_2=-.02 *p*=.34	r_2=-.03 *p*=.28	r_2=-.04 *p*=.19	r_2=-.02 *p*=.34
SPSI* Checklist 3	r_2=-.01 *p*=.34	r_2=-.01 *p*=.38	r_2=-.03 *p*=.23	r_2=-.03 *p*=.22
SPSI* Total	r_2=.01 *p*=.45	r_2=-.00 *p*=.48	r_2=-.01 *p*=.39	r_2=-.01 *p*=.40

**Sensory Processing Scale Inventory*

4.2.4. H_3: One or more sensory modulation subscales will predict unique variance in autism trait scores, when other relevant variables are taken into account.

A two-stage hierarchical multiple regression was performed with dependent variable AQ. Control variables age, gender, ethnicity, socioeconomic status and ACE-Q score were entered at step one. Categorical data were amalgamated into categories (see table eight) and dummy coded. Step two introduced the three modulation subscales as predictor variables.

Table eight:

Summary of Hierarchical Regression Analysis for Variables Predicting AQ Scores

Variable		□*β*	*t*	R^2	ΔR^2	*p*
[Constant]			4.29	.479	.463	<.001
Age		.05	1.32			.19
Gender	Male	.06	1.58			.12
	Non-binary/third gender	.13	3.60			<.001
	Other	.08	2.33			.02
	Prefer not to say	.11	3.23			.001
	Female (reference)	-	-			
Ethnicity	Asian or Asian British	-.03	-.91			.36
	Black, Black British, Caribbean or African	-.11	-3.21			.001
	Mixed or multiple ethnic groups	-.09	-2.80			.01
	Other	-.06	-1.72			.09
	White (reference)					
Socioeconomic status	Intermediate profession	-.04	-1.11			.27
	Low socioeconomic group	-.04	-1.14			.26
	Professional background (reference)					
ACE-Q* Scores		.02	.64			.52
Withdrawal		.60	14.46			<.001
Sensory seeking		-.07	-1.74			.08
Interpersonal		.06	1.31			.19

ACE-Q (Adverse Childhood Event Questionnaire)

Demographic variables contributed significantly to the model ($F(12,494)=9.989$, $p<.001$), accounting for 19.5% of the variance in AQ scores. The addition of modulation subscales also contributed significantly ($F(15,491)=30.118$, $p<.001$) and accounted for an additional 28.4% of the variance. Withdrawal significantly predicted AQ scores. Sensory seeking was approaching significance as a negative predictor.

4.2.5. *H4: One or more sensory modulation subscale will predict unique variance in ACE-Q scores, when other relevant variables are taken into account.*

A two-stage hierarchical multiple regression was performed with ACE-Q score as the dependent variable. Control demographic variables, as above, and AQ scores were entered at step one. Step two included the three modulation subscales as predictor variables.

Table nine:
Summary of Hierarchical Regression Analysis for Variables Predicting ACE-Q Scores

Variable		□*β*	*T*	R^2	ΔR^2	*p*
[Constant]			-.71	.20	.18	.48
Age		.05	1.21			.23
Gender	Male	.07	1.71			.09
	Non-binary/third gender	.10	2.20			.03
	Other	.04	.91			.36
	Prefer not to say	-.08	-1.92			.06
	Female (reference)	-	-			
Ethnicity	Asian or Asian British	.02	.39			.70
	Black, Black British, Caribbean or African	.02	.54			.59
	Mixed or multiple ethnic groups	.07	1.64			.10
	Other	-.00	-.04			.97
	White (reference)					
Socioeconomic status	Intermediate profession	.08	1.99			.05
	Low socioeconomic group	.07	1.67			.10
	Professional background (reference)					
AQ* Scores		.04	.64			.52
Withdrawal		.28	4.57			<.001
Sensory seeking		.01	.15			.88
Interpersonal		.13	2.43			.02

AQ (Autism Quotient Questionnaire – Adolescent)

Demographic variables contributed significantly to the model ($F(12,494)=9.989$, $p<.001$) and accounted for 10.9% of the variance in ACE-Q scores. The addition of the three subscales accounted for an additional 7.1% of the variance and contributed significantly ($F(15,491)=30.118$, $p<.001$). Withdrawal and interpersonal subscales significantly predicted ACE-Q scores.

4.2.6. H_5: Significant group differences will be found within sensory modulation subscale scores

A one-way ANCOVA was performed to explore sensory modulation differences between groups (see table 10), defined by AQ and ACE-Q cut-off scores (see appendix QQ, SS), controlling for age, gender, ethnicity and socio-economic status.

Table 10:

Summary of group demographic information

Demographic		**Autism (n=83)**	**Trauma (n=114)**	**Autism and Trauma (n=218)**	**Control (n=92)**
Gender	*Male*	12 (14.45%)	19 (16.67%)	26 (11.93%)	14 (15.22%)
	Female	43 (51.81%)	69 (60.53%)	83 (38.07%)	62 (67.39%)
	Non-binary/third gender	11 (13.25%)	15 (13.16%)	74 (33.94%)	8 (8.70%)
	Other	8 (9.64%)	9 (7.89%)	25 (11.47%)	6 (6.52%)
	Prefer not to say	9 (10.84%)	2 (1.75%)	10 (4.59%)	2 (2.17%)
Age		M(SD) = 14.9 (1.45), Median = 15	M(SD) = 14.8 (1.48), Median = 15	M(SD) = 14.8 (1.48), Median = 15	M(SD) = 15.0 (1.53), Median = 15
Ethnicity	*Asian and Asian British*	1 (1.20%)	2 (1.75%)	3 (1.37%)	2 (2.17%)
	Black, Black British, Caribbean or African	0 (0%)	7 (6.14%)	1 (.46%)	2 (2.17%)
	Mixed or multiple ethnic groups	2 (2.41%)	12 (10.53%)	7 (3.21%)	4 (4.35%)

	White	79 (95.18%)	91 (79.82%)	203 (93.12%)	81 (88.04%)
	Other ethnic group	1 (1.20%)	2 (1.75%)	4 (1.83%)	3 (3.26%)
Socioeconomic status[4]	*Professional background*	45 (54.22%)	63 (55.26%)	124 (56.88%)	58 (63.04%)
	Intermediate background	16 (19.27%)	26 (22.81%)	36 (16.51%)	17 (18.48%)
	Lower socioeconomic background	16 (19.27%)	20 (17.54%)	43 (19.72%)	8 (8.70%)
	Missing data	6 (7.23%)	5 (4.38%)	15 (6.88%)	9 (9.78%)

There was a significant effect of group on withdrawal ($F(3, 492)=66.017$, $p<.001$), sensory-seeking ($F(3, 492)=5.511$, $p<.001$) and interpersonal ($F(3, 492)=16.390$, $p<.001$) subscales, when controlling for covariates. Table 11 and 12 highlight group differences.

Table 11:

Estimated marginal means

Variable	Autism	Trauma	Both	Control
Withdrawal	23.92	21.50	28.44	17.28
Sensory seeking	11.89	11.89	13.11	10.61
Interpersonal	8.32	8.44	10.84	5.41

Table 12:

Summary of ANCOVA Results

Variable		*Autism vs trauma*	*Autism vs both*	*Trauma vs both*	*Autism vs Control*	*Trauma vs control*	*Both vs control*
Withdrawal	*Mean difference*	2.42	-4.51**	-6.94**	6.64**	4.22**	11.16**
	SE	.95	.85	.78	.99	.91	.83
Sensory seeking	*Mean difference*	-.09	-1.21	-1.13	1.28	1.37	2.50**

[4] Based on highest parental occupation. Occupations scored in line with government guidance (GOV.UK)

	SE	.72	.64	.59	.74	.69	.63
Interpersonal	*Mean difference*	-.12	-2.51*	-2.40*	2.91*	3.03*	5.42**
	SE	.90	.80	.74	.93	.86	.79

Based on estimated marginal means.
Adjusted for multiple comparisons: Bonferroni
**p=<.05*
***p=<.001*

See Appendix CCC for additional analyses.

5. Discussion

The Adolescent Sensory Coping Measure was developed through reviewing the literature and consulting experts and YP with experience of sensory sensitivities. EFA revealed three aspects of sensory modulation – sensory-seeking, withdrawal and interpersonal strategies. Both 'sensory-seeking' and 'withdrawal' factors map onto Dunn's Sensory Processing Model as active responses to high and low sensory thresholds (Dunn, 1997). The interpersonal factor was an important finding suggesting an important aspect of modulation for adolescents; expressing their discomfort to, and seeking support from, others.

Although the measure had good internal reliability and divergent validity, it had poor convergent validity with the SPSI. It is notable however that although the SPSI aimed to measure sensory modulation, items focused primarily on recognising hypersensitivities, whilst the current measure focuses mainly on active response strategies. This further highlights the need for a novel modulation measure to assess these strategies.

Withdrawal was found to be a significant predictor of both autism and ACE scores, an unsurprising finding as within the literature, withdrawal is a key hypersensitivity modulation strategy (Dunn, 1997) across many clinical groups (Moran, 2015; Ben-Sasson et al., 2008; Engel-Yeger et al., 2013; Brand-Gothelf et al., 2016; Mimouni-Bloch, 2018; Sharfi & Rosenbum, 2015; Olsen, 2011; Engel-Yeger et al., 2018). Withdrawal did not significantly differ between the autism and trauma groups, however it was approaching significance ($p=.068$) as higher in the autism group. This is an important finding as a possible distinguishable feature and should be further explored within the clinical population.

Furthermore, within the regression analysis differences in sensory-seeking and interpersonal strategies was found between autism and ACEs. Sensory-seeking was approaching significance as a unique negative predictor of AQ scores, whereas interpersonal strategies were a significant unique predictor of ACE scores; an important distinction when working clinically with YP. This is consistent with Moran (2015) who postulated that YP who have experienced ACEs direct their sensory responses towards caregivers to seek support, whereas autistic individuals are less likely to share their discomfort with others.

When comparing "pure" group scores via the ANCOVA however, results differed. Sensory-seeking and interpersonal subscales did not differ between the autism group and trauma groups. Additionally, autism and trauma groups sensory-seeking did not significantly differ to controls, and was only significantly higher in the combined autism and trauma group compared to controls. This is an interesting finding particularly when applied to the autistic population given the extent of literature around this topic and the inclusion of sensory sensitivities within the DSM-5 (APA, 2013). Although the ANCOVA and regression results do differ, it is possible this is due to the samples used. The regressions utilised overall ACE-Q and AQ score, however the ANCOVA was based on distinctive groups using clinical cut-off scores. Calculating the ANCOVA based on these groups however may have reduced the power to detect effects due to groups consisting of smaller samples. Additionally, as the sample was recruited via the general population, the analyses using distinct 'autism' and 'trauma' groups may not be truly representative of the clinical populations it intended to replicate, and therefore this should be taken into consideration when interpreting the findings.

According to Dunn (1997) sensory-seeking is a response to hyposensitivity, however few studies have explored the prevalence of hyposensitivities in autism and trauma. Some have

found higher rates of hyposensitivity/sensory-seeking in autistic YP compared to control groups (Brown et al., 2008; Chen et al., 2009; Ben-Sasson et al., 2007), whilst others report low incidence of sensory-seeking in autistic YP (Ermer & Dunn, 1998; Joosten & Bundy, 2010). Within this sample, it remains unclear whether sensory-seeking was in response to hyposensitivity or also occurred in response to hypersensitivities. This could usefully be explored in future research, particularly as it was a negative predictor. Hyposensitivities have also been linked to ACEs in the literature, and Engel-Yeger et al. (2013) found lower rates of sensory-seeking in adults with post-traumatic stress compared to typical adults. This could also be further explored. It should be noted that there are a high number of visually impaired young people within the sample, and visual impairment are linked to increased sensory processing difficulties (Houwen et al., 2022) within the general population.

This research revealed helpful domains of sensory modulation for adolescents which should be considered within clinical practice. Considering these sensory modulation domains within the therapeutic assessment and intervention will allows for a greater understanding of the young person's experiences and responses for the clinician, the young person themselves, and the system around the young person such as their family. This newly developed measure can be used to further aid the assessment and conversation.

Furthermore, although further research is needed, these preliminary findings may support clinicians in the distinction between autism and a trauma response when considered alongside other information. For example, clinicians may wish to draw on the finding that interpersonal strategies are more closely linked to ACES than autism.

Limitations and future directions:

This study addressed a gap in self-report adolescent sensory modulation tools and allowed an exploration of sensory modulation between two clinical groups. Although groups were defined using clinical cut-offs of two measures, the sample was recruited from a non-clinical population, and therefore results cannot be generalised to the clinical population. Future research would benefit from applying the new measure to clinical groups to allow for greater confidence in the findings and further explore group differences.

The development of this measure focused predominantly on active strategies based on the literature and consultations, suggesting that passive strategies may be less reported or discussed. Further research may benefit from exploring passive strategies, and other aspects of the Dunn's model, in more detail. Additionally, it was recommended within the professionals focus group that a parent-report measure alongside the self-report measure may be a useful tool in clinical practice to further assist families understanding of the young person's experience and allow for further insights for the young person. Future research should consider the development of this additional measure. As with the current measure, this should be developed in consultation with experts by experience.

Additionally, the ACEs measure collected number of traumas only, not allowing for comparisons between the types of ACEs experienced. This may have impacted results and led to interesting findings regarding modulation strategies, particularly as the autism and trauma overlap is discussed most frequently in relation to interpersonal and attachment traumas (e.g. Moran 2010; 2015; McKenzie, 2017).

Despite this study exploring a key aspect of the Coventry Grid (Moran, 2010), there are many other components that overlap across autism and a trauma response that need further exploration before we can confidently distinguish between the two presentations. Further research is needed to explore each of these domains discussed within the Coventry Grid (Moran, 2010) to build a complete picture of the discrepancies, where there are any.

Using a broad inclusion/exclusion criteria facilitated heterogeneity and allowed typically underrepresented groups to be represented in this research. However, as recruitment was largely completed via social media, this may have excluded certain groups from participating. It is worth noting that the completion rate of the questionnaire was low (33.7%) perhaps impacted by the time-demand. Counterbalancing the different questionnaires within the survey may have allowed for further data collection, particularly for the newly developed sensory modulation measure which was placed at the end of the survey for all participants. Additionally, a high proportion of participants reported visual impairments. This was not clearly defined within the questionnaire and therefore may not be a true representation of the sample. This should however be considered when interpreting the results given that sensory processing difficulties may be higher than average in the control group as a result (Houwen et al., 2022).

Despite these limitations, this study has allowed for a further exploration of Dunn's Model and highlighted a possible extension pertaining to interpersonal strategies. The study has built upon Moran's anecdotal work exploring differences between autism and responses to trauma with a focus on sensory modulation. Although this measure confirmed some aspects of

Dunn's model, exploring all dimensions of the model using the clinical population would be useful.

6. References

American Psychiatric Association. (2013). Neurodevelopmental disorders. In *Diagnostic and statistical manual of mental disorders* (5th ed., text rev.).

Anda, R. F., Butchart, A., Felitti, V. J., & Brown, D. W. (2010). Building a framework for global surveillance of the public health implications of adverse childhood experiences. *American journal of preventive medicine*, *39*(1), 93-98.

Ayres, A. J. (1972). *Sensory integration and learning disorders.* Los Angeles, CA: Western Psychological Services.

Ayres, A. J. (1989). *Sensory Integration and Praxis Tests Manual.* Los Angeles: Western Psychological Services.

Baranek, G. T., David, F. J., Poe, M. D., Stone, W. L., & Watson, L. R. (2006). Sensory Experiences Questionnaire: discriminating sensory features in young children with autism, developmental delays, and typical development. *Journal of Child Psychology and Psychiatry, 47(6),* 591-601.

Baron-Cohen, S., Hoekstra, R. A., Knickmeyer, R., & Wheelwright, S. (2006). The autism-spectrum quotient (AQ)—adolescent version. *Journal of autism and developmental disorders*, *36*(3), 343-350.

Ben-Sasson, A., Cermak, S. A., Orsmond, G. I., Tager-Flusberg, H., Kadlec, M. B., & Carter, A. S. (2008). Sensory clusters of toddlers with autism spectrum disorders: Differences in affective symptoms. *Journal of Child Psychology and Psychiatry, 49*(8), 817-825.

Burke Harris, N. and Renschler, T. (2015). Center for Youth Wellness ACE-Questionnaire *(CYW ACE-Q Child, Teen, Teen SR).* Center for Youth Wellness. San Francisco, CA.

Brand-Gothelf, A., Parush, S., Eitan, Y., Admoni, S., Gur, E., & Stein, D. (2016). Sensory modulation disorder symptoms in anorexia nervosa and bulimia nervosa: A pilot study. *International Journal of Eating Disorders, 49(1),* 59-68.

Cronholm, P. F., Forke, C. M., Wade, R., Bair-Merritt, M. H., Davis, M., Harkins-Schwarz, M., ... & Fein, J. A. (2015). Adverse childhood experiences: Expanding the concept of adversity. *American journal of preventive medicine, 49*(3), 354-361.

Dunn. (2014). *Sensory Profile 2 manual.* San Antonio, TX: Pearson.

Dunn, W. (1997). The Impact of Sensory Processing Abilities on the Daily Lives of Young Children and Their Families: A Conceptual Model. *Inf Young Children, 9(4),* 23-35.

Centers for Disease Control and Prevention. (2018). *Data & Statistics on Autism Spectrum Disorder. Water-related diseases and contaminants in public water systems.* Autism Spectrum Disorder. https://www.cdc.gov/ncbddd/autism/data.html

Cermak, S. and May-Benson, T., 2020. Praxis and Dyspraxia. In: A. Bundy and S. Lane, ed., *Sensory Integration Theory and Practice*, 3rd ed. Philadelphia: F. A. Davis Company, p.115.

Cincinnati Children's. (2017). *Childhood Trust Events Survey-Caregiver and Child Version (CTES) and Adolescent Version (CTES-A) [Measurement instrument]. Cincinatti, OH. http://cincinnatichildrens.org/service/childhood-trust/events-survey*

Comrey, A. L. and Lee, H. B., (1992), A first course in factor analysis, Hillsdale, New Jersey: Erlbaum

Cronholm, P. F., Forke, C. M., Wade, R., Bair-Merritt, M. H., Davis, M., Harkins-Schwarz, M., … & Fein, J. A. (2015). Adverse childhood experiences: Expanding the concept of adversity. *American journal of preventive medicine*, *49*(3), 354-361.

Dancey, C. P., & Reidy, J. (2007). *Statistics without maths for psychology*. Pearson education.

Eeles, A., Spittle, A. J., Anderson, P. J., Brown, N., Lee, K., Boyd, R., & et al.,. (2013). Assessment of sensory processing in infant: a systematic review. *Dev Med Child Neurol, 55*, 314-326.

Engel-Yeger, B., Bloch, B., Gonda, X., Canepa, G., Pompili, M., Sher, L., ... & Serafini, G. (2018). Sensory profiles in unipolar and bipolar affective disorders: Possible predictors of response to antidepressant medications? A prospective follow-up study. *Journal of Affective Disorders*, *240*, 237-246.

Engel-Yeger, B., Palgy-Levin, D., & Lev-Wiesel, R. (2013). The Sensory Profile of People with Post-Traumatic-Stress Symptoms. *Occupational Therapy in Mental Health, 29(3)*, 266-278.

George, D., & Mallery, P (2003). *SPSS for Windows step by step: A simple guide and reference. 11.0 Update.* (4th ed.). Bosten: Allyn & Bacon.

Green, J., Leadbitter, K., Kay, C., & Sharma, K. (2016). Autism spectrum disorder in children adopted after early care breakdown. *Journal of Autism and Developmental Disorders*, *46*(4), 1392-1402.

Harrison, L. A., Kats, A., Williams, M. E., & Aziz-Zadeh, L. (2019). The Importance of Sensory Processing in Mental Health: A Proposed Addition to the Research Domain Criteria

(RDoC) and Suggestions for RDoC 2.0. *Frontiers in Psychology, 10(103),* https://doi.org/10.3389/fpsyg.2019.00103.

Holbrook, H., O'Loughlin, K., Athoff, R., Kaufman, J., &Hudziak, J. (2014). *The Yale-Vermont Adversity in Childhood Scale: A quantative approach to adversity assessment.* Retrieved from: https://www.researchgate.net/publication/267893082_The_Yale-Vermont_Adversity_in_Childhood_Scale_A_Quantitative_Approach_to_Adversity_Assessment

Hoover, D. W., & Kaufman, J. (2018). Adverse childhood experiences in children with autism spectrum disorder. *Current opinion in psychiatry*, *31*(2), 128.

Houwen, S., Cox, R. F., Roza, M., Lansink, F. O., van Wolferen, J., & Rietman, A. B. (2022). Sensory processing in young children with visual impairments: Use and extension of the Sensory Profile. *Research in Developmental Disabilities*, *127*, 104251.

Hughes, K., Bellis, M. A., Hardcastle, K. A., Sethi, D., Butchart, A., Mikton, C., ... Dunne, M. P. (2017). The effect of multiple adverse childhood experiences on health: A systematic review and meta-analysis. Lancet Public Health, 2(8), e356–e366. doi:10.1016/ S2468-2667(17)30118-4

Jorquera-Cabrera, S., Romero-Ayuso, D., Rodriguez-Gil, G., & Triviño-Juárez, J.-M. (2017). Assessment of Sensory Processing Characteristics in Children between 3 and 11 Years Old: A Systematic Review. *Child and Adolescent Psychiatry, 57(5).*

Kaiser, H. F., & Rice, J. (1974). Little jiffy, mark IV. *Educational and psychological measurement*, *34*(1), 111-117.

Kerns, C. M., Newschaffer, C. J., & Berkowitz, S. J. (2015). Traumatic childhood events and autism spectrum disorder. *Journal of autism and developmental disorders*, *45*(11), 3475-3486.

Kildahl, A. N., Helverschou, S. B., Bakken, T. L., & Oddli, H. W. (2020). "If we do not look for it, we do not see it": Clinicians' experiences and understanding of identifying post-traumatic stress disorder in adults with autism and intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, *33*(5), 1119-1132.

Krejcie, R. V., & Morgan, D. W. (1970). Determining sample size for research activities. *Educational and psychological measurement*, *30*(3), 607-610.

Lane, A. E., Young, R. L., Baker, A. E., & Angley, M. T. (2010). Sensory Processing Subtypes in Autism: Association with Adaptive Behaviour. *J Autism Dev Disord*, *40*, 112-122.

Lee, D., Jerman, P., Boparai, S. K. P., Koita, K., Briner, S., Bucci, M., & Harris, N. B. (2018). Review of tools for measuring exposure to adversity in children and adolescents. *Journal of Pediatric Health Care*, *32*(6), 564-583.

Mangeot, S. D., Miller, L. J., McIntosh, D. N., McGrath-Clarke, J., Simon, J., Hagerman, R. J., & Goldson, E. (2001). Sensory modulation dysfunction in children with attention-deficit-hyperactivity disorder. *Developmental Medicine & Child Neurology*, *43*, 399-406.

McKenzie, R., & Dallos, R. (2017). Autism and attachment difficulties: Overlap of symptoms, implications and innovative solutions. *Clinical child psychology and psychiatry*, *22*(4), 632-648.

Meltzer, H., Gatward, R., Goodman, R., & Ford, T. (2003). Mental health of children and adolescents in Great Britain. *International review of Psychiatry*, *15*(1-2), 185-187.

Mimouni-Bloch, A., Offek, H., Rosenblum, S., Posener, I., Silman, Z., & Engel-Yeger, B. (2018). Association between sensory modulation and daily activity function of children with attention deficit/hyperactivity disorder and children with typical development. *Research in Developmental Disabilities*, *83*, 69-76.

Moran, H. (2010). Clinical observations of the differences between children on the autism spectrum and those with attachment problems: The Coventry Grid. *Good Autism Practice Journal, 11(2)*, 46-59.

Niutanen, U., Harra, T., Lano, A. & Metsaranta, M. (2020). Systematic review of sensory processing in preterm children reveals abnormal sensory modulation, somatosensory processing and sensory-based motor processing. *Acta Paediatrica*, *109*, 45-55

Olson, L. (2011). *Sensory Modulation Disorder and Schizophrenia: Linking Behavioral Measures.* Virginia: Medicine and Health Sciences Commons.

Paull, S. (2015). *Elsie Allen Health Center ACE Survey.* Retrieved from https://acestoohigh.files.wordpress.com/2015/10/acesquestions.pdf

Rutter, M., Andersen-Wood, L., Beckett, C., Bredenkamp, D., Castle, J., Groothues, C., ... & O'Connor, T. G. (1999). Quasi-autistic patterns following severe early global privation. *The Journal of Child Psychology and Psychiatry and Allied Disciplines*, *40*(4), 537-549.

Sadiq, F. A., Slator, L., Skuse, D., Law, J., Gillberg, C., & Minnis, H. (2012). Social use of language in children with reactive attachment disorder and autism spectrum disorders. *European child & adolescent psychiatry*, *21*(5), 267-276.

Schoen, S. A., Miller, L. J., & Sullivan, J. (2017). The development and psychometric properties of the Sensory Processing Scale Inventory: A report measure of sensory modulation. *Journal of Intellectual & Developmental Disability*, *42*(1), 12-21.

Sharfi, K., & Rosenblum, S. (2015). Sensory modulation and sleep quality among adults with learning disabilities: A quasi-experimental case-control design study. *PloS one*, *10*(2), e0115518.

Stack, A., & Lucyshyn, J. (2019). Autism spectrum disorder and the experience of traumatic events: review of the current literature to inform modifications to a treatment model for children with autism. *Journal of autism and developmental disorders*, *49*(4), 1613-1625.

Sears, C. (1994). Recognising and coping with tactile defensiveness in young children. *Inf Young Children, (4)6*, 46-53.

Tabachnick, B. G., Fidell, L. S., & Ullman, J. B. (2007). *Using multivariate statistics* (Vol. 5, pp. 481-498). Boston, MA: pearson.

Executive Summary

Introduction:

We experience sensory input all the time. This includes things we see, hear, touch, taste, smell, and feel in our bodies. Individuals have different levels for how much we register different sensory input, and this can change depending on the situation, type of input, and how we feel. Our response to sensory input also ranges from more passive strategies (e.g. staying in a noisy place and feeling uncomfortable) to more active strategies (e.g. leaving the noisy place).

Sensory differences are recognised in many different presentations, including autism and responses to adverse childhood events (ACEs)/ trauma. Autism and trauma responses can have very similar presentations, which can make it more difficult for these individuals to reach the best support quickly. One of the ways that they might differ, is how they manage their sensory experiences. Currently, there is no research that has looked at this, and unfortunately no suitable measures to help us explore this. This study therefore aimed to develop an adolescent sensory coping measure which would allow us to explore any sensory management differences.

Method:

Seven professionals working with young people with sensory sensitivities and nine young people who experience sensory sensitivities supported with item development for the questionnaire, and consulted on the layout, wording and formatting of the questionnaire. A total of 507 young people (13-18 year olds) completed the final online questionnaire, along with other measures measuring autism traits and the number of adverse life events they have experienced.

Results:

The Adolescent Sensory Coping Measure, a 25-item questionnaire, was developed consisting of three subscales; withdrawal from sensory input, sensory-seeking, and interpersonal strategies. The measure had good internal consistency and reasonable divergent validity. Unfortunately, it had poor convergent validity when compared to another sensory measure, however this may have been due to them both seemingly measuring slightly different constructs.

The three sensory modulation subscales accounted for unique variance in both autism and ACE scores. In one analysis, the withdrawal subscale predicted both autism and ACE scores, and the sensory-seeking subscale appeared to negatively predict autism scores, whereas the interpersonal strategies subscale significantly predicted the ACE scores. This was not replicated in the analysis below however, perhaps due to using an overall autism and ACE score, rather than clinical cut-offs (as was done below).

Participants were split into four groups; those with high autism scores (autism group), those with high ACE scores (trauma group), those with high autism and ACE scores (both), and those with low autism and low ACE scores (control group), specified through the measures' clinical cut-offs. Analyses highlighted significant differences between most groups on the withdrawal subscale, with autism approaching significance as being higher in the autism group compared to the trauma group. On the interpersonal subscale, all the groups differed, except for the autism group and the trauma group. On the sensory-seeking subscale, only the 'both' group and control group differed.

Conclusion:

This study has provided a self-report adolescent measure exploring sensory modulation/coping, which allowed for the investigation of differences between individuals with autism traits, and those who have experienced ACEs. Analyses suggested that one difference in their sensory modulation may be the use of withdrawal, which was approaching significance and higher in the autism group compared to the trauma group. Further research should continue this exploration using clinical groups with a focus on hypo and hypersensitivity coping strategies.

Connecting Narrative

Coming into clinical training, I was keen to develop and strengthen my research skills as it was something I felt was extremely important within the role, and something I had enjoyed in previous posts. It took a little time for me to land on the specific projects as I wanted to ensure that I was passionate about the area and that it was going to have an impact. Unfortunately, the pandemic brought about several challenges including delays and one project being unable to go ahead. This gave me an appreciation of the need to be flexible and adapt to the situation, which feels extremely relevant when conducting research within the NHS.

Systemic Review of the Literature

I have worked with the autistic population throughout my career, and therefore I was acutely aware of the lack of representation within the literature, particularly in the evidence base for psychological interventions. Although some guidance existed around how to adapt the recommended interventions for this population, this appeared vague and related mainly to the process of therapy such as how it was delivered rather than what was delivered. I was curious about what adaptations were generally being adopted in practice and what the impact of these adaptations might be. When choosing our parameters of this review however, we were struck by the lack of published work regarding adapted CBT for autistic individuals across the majority of clinical presentations. For this reason, we chose to focus on anxiety-based CBT interventions, however this did give me an appreciation of how limited the evidence base is for other disorders and encouragement to document and publish more clinical work with this population.

I thoroughly enjoyed completing this systematic review as it provided a clearer view of what adaptations were being included in interventions, and the vast range of these. Although I was disappointed we were unable to provide clarity regarding what adaptations should be included in the guidance, I was pleased we had identified a need for further work in this area, something I am keen to continue.

Service Improvement Project

My initial plan for the service improvement project unfortunately was unable to continue due to the pandemic putting a stop to the normal running of community mental health services. Despite this, I felt I wanted to be 'useful' and contribute to healthcare services during this really uncertain and scary time. I was working within a hospital setting during the first wave, and my supervisor and I were keen to think about the impact of the pandemic on the staff and their ability to support patients. As training had already been completed with staff members working with patients with dementia and delirium on the ward, we were curious about how the pandemic had impacted these vulnerable individuals and staff members' capability to implement what was discussed. Thinking about staff wellbeing, identifying gaps for patients and where further support might be useful during this frightening time felt like really important work and where we could contribute most meaningfully as two of the very few psychologists within the hospital. Completing this work allowed me to gain greater insight into NHS systems, particularly during times of crisis, and at various levels of the hierarchy. I developed an appreciation for the really challenging decisions that needed to be made for the safety of the patients and staff. More than anything, I developed a strong appreciation for staff members who had made sacrifices to continue providing important care for patients and I was so pleased that I could be an advocate for them through this project and allow their

voices to be heard regarding what would support them to continue doing the wonderful work they were doing, which hopefully also resulted in an improvement in care. I was able to recognise how important completing service improvement projects within our services is, and I am keen to continue this practice when qualified.

Theoretically Driven Research Project

This project was also not without challenges, however it was certainly the project I was most passionate and proud of. I have been very interested in the diagnostic overlap between autism and trauma/attachment and therefore when this project came up I was very excited to be able to contribute to this area. Before we could explore this in relation to sensory modulation however, we recognised there was a need for a sensory modulation measure, and therefore I was keen to develop this. In order to do so, I collected feedback and ideas from key stakeholders including professionals working with these two populations as well as young people who identified as having these difficulties. This gave me an appreciation of the importance of collaboration and coproduction in research, and I learned so much from this process. I was also struck by how many young people wanted to participate in completing the questionnaire, and this just confirmed how important it is that we develop a self-report measure to ensure we are capturing the voices of young people.

I found exploring the results of this project extremely interesting, and I spent several weeks looking at and analysing the data. I developed key skills in exploratory factor analysis and the development of a new questionnaire, as well as analysing differences between groups. Given the lack of literature on sensory modulation differences across the two clinical presentations, I was unsure if we would find any significant differences between the groups. It was very exciting therefore when the analyses revealed some potential differences between those with

high autism scores and those with high ACE scores. The findings also highlighted some areas for future research to continue to explore these potential differences, something that I am keen to continue to do.

This project was challenging as delays were experienced in many aspects of the study. However, being able to work with key stakeholders in the development of the measure and completing the analyses reaffirmed my enthusiasm to continue contributing to the research field, and particularly in expanding this research to the underrepresented populations.

Acknowledgements

I owe my gratitude to all the individuals who took part in the research studies. I worked with amazing professionals and young people who made significant contributions to the research, either through consulting on the research study, or taking part, for which I am very grateful. I have learnt a lot from every interaction and individual. I would also like to thank the Child and Adolescent Mental Health Services for advertising and supporting with recruitment for the final theory driven project; and for the ward staff for supporting with recruitment for the service improvement project.

I am so grateful to the wonderful internal and external supervisors who provided so much guidance and support across the three projects including Dr Fin Williams, Dr Joanne Cocksey, Prof. Craig Steel, Dr Helen Cressey, Dr Myra Cooper, Dr James Stacey and Dr Carmen Chan. I would also like to thank Dr Sarah Coles who supported and supervised the critical review of the literature project over the first few months of the project, whose guidance was extremely valuable. Throughout my training I was lucky enough to also have been supported by Dr Matthew Knight as my course tutor and I am extremely grateful for his compassion and guidance throughout the three years.

I want to also thank the DClinPsy 2019 cohort, my friends and family for their support and understanding throughout this journey and for constantly cheering me on. Finally, I want to thank my husband for supporting me through the many highs and lows, for his endless encouragement, his unwavering understanding and support, and for always believing I could do this. I most certainly would not have been able to do this without him. Thank you.

Appendices

Appendix A: CRL – Search terms

The following search terms were used to initially identity papers:

1	Autism OR ASD OR Asperger* OR PDD-NOS OR “pervasive developmental delay not otherwise specified”
	CBT OR “cognitive behavio* therap*”
3	Anxiet*
4	Child OR adolescen* OR “young pe*”
	1 AND 2 AND 3 AND 4

Appendix B: CRL - Downs and Black Quality Assessment Tool

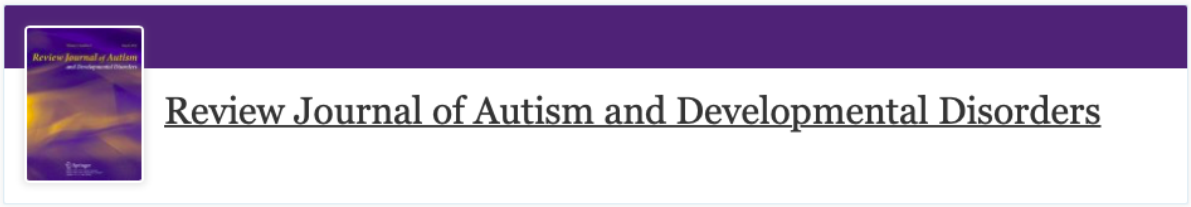
	Reporting		**Score**
1	Is the hypothesis/aim/objective of the study clearly described?	Yes=1, No=0	
2	Are the main outcomes to be measured clearly described in the Introduction or Methods section?	Yes=1, No=0	
3	Are the characteristics of the participants included in the study clearly described?	Yes=1, No=0	
4	Are the interventions of interest clearly described?	Yes=1, No=0	
5	Are the distributions of principal confounders in each group of subjects to be compared clearly described?	Yes=2, Partially=1, No=0	
6	Are the main findings of the study clearly described?	Yes=1, No=0	
7	Does the study provide estimates of the random variability in the data for the main outcomes?	Yes=1, No=0	
8	Have all important adverse events that may be a consequence of the intervention been reported?	Yes=1, No=0	
9	Have the characteristics of patients lost to follow-up been described?	Yes=1, No=0	
10	Have actual probability values been reported?	Yes=1, No=0	
	External Validity		**Score**
11	Were the subjects asked to participate in the study representative of the entire population from which they were recruited?	Yes=1, No=0, Unable to determine=0	
12	Were those subjects who were prepared to participate representative of the entire population from which they were recruited?	Yes=1, No=0, Unable to determine=0	
13	Were the staff, places, and facilities where the patients were treated, representative of the treatment the majority of patients received?	Yes=1, No=0, Unable to determine=0	
	Internal Validity - Bias		**Score**

14	Was an attempt made to blind study subjects to the intervention they have received?	Yes=1, No=0, Unable to determine=0	
15	Was an attempt made to blind those measuring the main outcomes of the intervention?	Yes=1, No=0, Unable to determine=0	
16	If any the results of the study were based on "data dredging, was this made clear?	Yes=1, No=0, Unable to determine=0	
17	In trials and cohort studies, do the analyses adjust for different lengths of follow-up of patients, or in case-control studies, is the time period between the intervention and outcomes the same for cases and controls?	Yes=1, No=0, Unable to determine=0	
18	Were the statistical tests used to assess the main outcomes appropriate?	Yes=1, No=0, Unable to determine=0	
19	Was compliance with the intervention/s reliable?	Yes=1, No=0, Unable to determine=0	
20	Were the main outcome measures used accurate (valid and reliable)?	Yes=1, No=0, Unable to determine=0	
	Internal Validity – Confounding (Selection Bias)		**Score**
21	Were the patients in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited from the same population?	Yes=1, No=0, Unable to determine=0	
22	Were study participants in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited over the same period of time?	Yes=1, No=0, Unable to determine=0	
23	Were study participants randomised to intervention groups?	Yes=1, No=0, Unable to determine=0	
24	Was the randomised intervention assignment concealed from both patients and health care staff until recruitment was complete and irrevocable?	Yes=1, No=0, Unable to determine=0	

25	Was there adequate adjustment for confounding in the analyses from which the main findings were drawn?	Yes=1, No=0, Unable to determine=0	
26	Were losses of patients to follow-up taken into account?	Yes=1, No=0, Unable to determine=0	
	Power	**Yes/No**	**Score**
27	Did the study carry out power calculation?	Yes=1, No=0	
	TOTAL SCORE		

This was a modified version of the Downs and Black checklist. Question 27 was adapted from the original question "Did the study have sufficient power to detect a clinically important effect where the probability value for a difference being due to chance is less than 5%?" in line with recommendations from Kennelly (2011, cited by Irons, Sheffield, Ballington & Stewert, 2019).
The calculations were completed based on the number of items that were able to be scored, excluded those marked as N/A. An average score was then calculated in order to compare against the benchmarks for poor, fair, good and excellent quality.

Appendix C: CRL – Journal submission guidelines



Review Journal of Autism and Developmental Disorders

Submission guidelines

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Instructions for Authors

Editorial procedure

Double-blind peer review

The Journal uses a double-blind review process. Therefore, when submitting a new manuscript, DO NOT include any of your personal information (e.g., name, affiliation) anywhere within the manuscript. When you are ready to submit a manuscript to RJAD, please be sure to upload these 3 separate files to the Editorial Manager site to ensure timely processing and review of your paper:

- A title page with the running head, manuscript title, and complete author information. Followed by (page break) the Abstract page with keywords and the corresponding author e-mail information.
- The blinded manuscript containing no author information (no name, no affiliation, and so forth).
- The Author Note

Types of papers

• **Review Articles:** The preferred article length is 20-23 manuscript pages long (not including title page, abstract, tables, figures, addendums, etc.) Manuscripts of 40 pages (references, tables and figures counted as pages) have been published. The reviewers or the editor for your review will advise you if a longer submission must be shortened.

• **Brief Report:** The purpose of the concise review is to summarize literature on a specific topic and provide directions for future research or for improvement in clinical practice. Authors interested in writing a brief review should send an abstract and reference list to the Editor (Jill Fodstad, PhD) for initial consideration prior to standard peer review process. Please contact Dr. Fodstad at jfodstad@iupui.edu. Articles should be no more than 2,500 total words, not including the Title Page, Author Note, References, and Tables/Figures. Max of 2 Tables/Figures. No Supplementary Material. May fall under one of two areas:

- Concise narrative review: Highly focused narrative review on one specific segment of the literature that is of clinical relevance. Topics can have a fragmentary evidence base, such as emerging issues, singular events, or new approaches. Title should specify that the report is a narrative review. Aim/purpose of review should be clearly stated with authors including a statement of what this narrative review adds to the literature. The structure/organization can be organic, taking its organization from the topic, rather than forced into that of an original scientific contribution. No more than 20% of references should be self-citations of corresponding/co-authors

- Concise systematic review: Highly focused systematic review on one specific segment of the literature. Title should specify that the report is a brief/concise systematic review. Aim/purpose of review should be clearly stated with authors including a statement of what this concise systematic review adds to the literature. Using the appropriate standardized reporting format guidelines (e.g., PRIMSA; ENTREQ) are strongly suggested, but not a requirement. To be of benefit, should focus primarily on research published during the preceding five years. No more than 20% of references should be self-citations of corresponding/co-authors. This type of brief report can be considered a brief systematic, scoping, meta-analysis, meta-syntheses, or other data-driven review of the literature.

Review your manuscript for these elements

Order of manuscript pages

- Title Page with all Author Contact Information & Abstract with keywords and the corresponding author e-mail information.
- Blinded Manuscript without contact information and blinded Abstract, and References
- Appendix
- Figure Caption Sheet
- Figures
- Tables
- Author Note

Manuscript Submission

Manuscript Submission

Submission of a manuscript implies: that the work described has not been published before; that it is not under consideration for publication anywhere else; that its publication has been approved by all co-authors, if any, as well as by the responsible authorities – tacitly or explicitly – at the institute where the work has been carried out. The publisher will not be held legally responsible should there be any claims for compensation.

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Please follow the hyperlink “Submit manuscript” and upload all of your manuscript files following the instructions given on the screen.

Source Files

Please ensure you provide all relevant editable source files at every submission and revision. Failing to submit a complete set of editable source files will result in your article not being considered for review. For your manuscript text please always submit in common word processing formats such as .docx or LaTeX.

Title page

The title page should include:

- The name(s) of the author(s)

- A concise and informative title
- The affiliation(s) and address(es) of the author(s)
- The e-mail address of the corresponding author

Abstract

Please provide an abstract of 120 words or less. The abstract should not contain any undefined abbreviations or unspecified references.

Keywords

Please provide 4 to 6 keywords which can be used for indexing purposes.

Text

Text Formatting

Manuscripts should be submitted in Word.

- Use a normal, plain font (e.g., 10-point Times Roman) for text.
- Use italics for emphasis.
- Use the automatic page numbering function to number the pages.
- Do not use field functions.
- Use tab stops or other commands for indents, not the space bar.
- Use the table function, not spreadsheets, to make tables.
- Use the equation editor or MathType for equations.
- Save your file in docx format (Word 2007 or higher) or doc format (older Word versions).

Headings

Please use no more than three levels of displayed headings.

Abbreviations

Abbreviations should be defined at first mention and used consistently thereafter.

Footnotes

Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables.

Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data). Footnotes to the title or the authors of the article are not given reference symbols.

Always use footnotes instead of endnotes.

Acknowledgments

Acknowledgments of people, grants, funds, etc. should be placed in a separate section on the title page. The names of funding organizations should be written in full.

Body

- The body of the manuscript should begin on a separate page. The manuscript page header (if used) and page number should appear in the upper right corner. Type the title of the paper centered at the top of the page, add a hard return, and then begin the text using the format noted above. The body should contain: Introduction (The introduction has no label.) Methods (Center the heading. Use un-centered subheadings such as: Participants, Materials, Procedure.) Results (Center the heading.) Discussion (Center the heading.)
- HeadingsPlease use no more than three levels of displayed headings. Level 1: Centered Level 2: Centered Italicized Level 3: Flush left, Italicized
- Footnotes Center the label “Footnotes” at the top of a separate page. Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables. Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data). Footnotes to the title or the authors of the article are not given reference symbols. Always use footnotes instead of endnotes. Type all content footnotes and copyright permission footnotes together, and numbered consecutively in the order they appear in the article. Indent the first line of each footnote 5-7 spaces. The number of the footnote should correspond to the number in the text. Superscript arabic numerals are used to indicate the text material being footnoted.
- Author NoteThe first paragraph contains a separate phrase for each author’s name and the affiliations of the authors at the time of the study (include region and country).The second paragraph identifies any changes in the author affiliation subsequent to the time of the study and includes region and country (wording: “authors name is now at affiliation”.) The third paragraph is Acknowledgments. It identifies grants or other financial support and the source, if appropriate. It is also the place to acknowledge colleagues who assisted in the study and to mention any special circumstances such as the presentation of a version of the paper at a meeting, or its preparation from a doctoral dissertation, or the fact that it is based on an earlier study. The fourth paragraph states, “Correspondence concerning this article should be addressed to…” and includes the full address, telephone number and email address of the corresponding author.

Terminology

- Please always use internationally accepted signs and symbols for units (SI units).

Scientific style

- Generic names of drugs and pesticides are preferred; if trade names are used, the generic name should be given at first mention.
- Please use the standard mathematical notation for formulae, symbols etc.:Italic for single letters that denote mathematical constants, variables, and unknown quantities Roman/upright for numerals, operators, and punctuation, and commonly defined functions or abbreviations, e.g., cos, det, e or exp, lim, log, max, min, sin, tan, d (for derivative) Bold for vectors, tensors, and matrices.

References

Citation

Cite references in the text by name and year in parentheses. Some examples:

- Negotiation research spans many disciplines (Thompson 1990).

- This result was later contradicted by Becker and Seligman (1996).
- This effect has been widely studied (Abbott 1991; Barakat et al. 1995; Kelso and Smith 1998; Medvec et al. 1999).

Reference list

The list of references should only include works that are cited in the text and that have been published or accepted for publication. Personal communications and unpublished works should only be mentioned in the text. Do not use footnotes or endnotes as a substitute for a reference list.

Reference list entries should be alphabetized by the last names of the first author of each work.

- Journal article
  Harris, M., Karper, E., Stacks, G., Hoffman, D., DeNiro, R., Cruz, P., et al. (2001). Writing labs and the Hollywood connection. Journal of Film Writing, 44(3), 213-245
- Article by DOI
  Slifka, M. K., & Whitton, J. L. (2000) Clinical implications of dysregulated cytokine production. Journal of Molecular Medicine, doi:10.1007/s001090000086
- Book
  Calfee, R. C., & Valencia, R. R. (1991). APA guide to preparing manuscripts for journal publication. Washington, DC: American Psychological Association.
- Book chapter
  O'Neil, J. M., & Egan, J. (1992). Men's and women's gender role journeys: Metaphor for healing, transition, and transformation. In B. R. Wainrib (Ed.), Gender issues across the life cycle (pp. 107–123). New York: Springer.
- Online document
  Abou-Allaban, Y., Dell, M. L., Greenberg, W., Lomax, J., Peteet, J., Torres, M., & Cowell, V. (2006). Religious/spiritual commitments and psychiatric practice. Resource document. American Psychiatric Association. http://www.psych.org/edu/other_res/lib_archives/archives/200604.pdf. Accessed 25 June 2007.

Journal names and book titles should be italicized.

Tables

- All tables are to be numbered using Arabic numerals.
- Tables should always be cited in text in consecutive numerical order.
- For each table, please supply a table caption (title) explaining the components of the table.
- Identify any previously published material by giving the original source in the form of a reference at the end of the table caption.
- Footnotes to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data) and included beneath the table body.

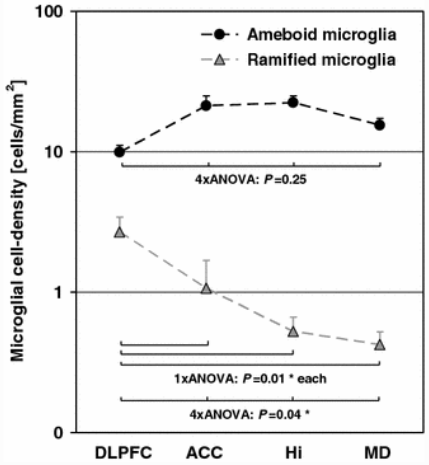
Each table should be inserted on a separate page at the back of the manuscript in the order noted above. A call-out for the correct placement of each table should be included in brackets within the text immediately after the phrase in which it is first mentioned. Copyright permission footnotes for tables are typed as a table note.

Artwork and Illustrations Guidelines

Electronic Figure Submission

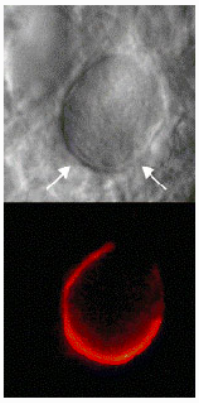
- Supply all figures electronically.
- Indicate what graphics program was used to create the artwork.
- For vector graphics, the preferred format is EPS; for halftones, please use TIFF format. MSOffice files are also acceptable.
- Vector graphics containing fonts must have the fonts embedded in the files.
- Name your figure files with "Fig" and the figure number, e.g., Fig1.eps.

Line Art



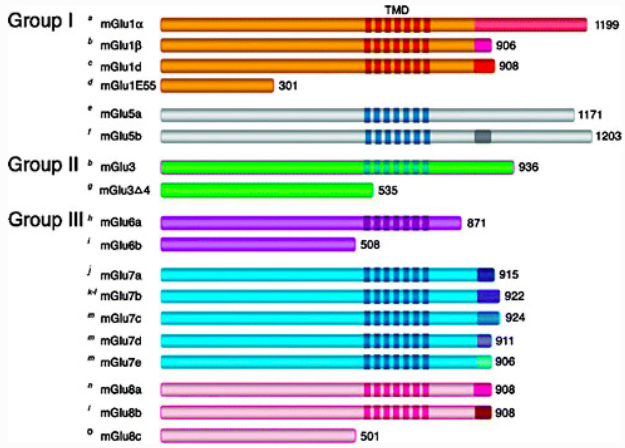
- Definition: Black and white graphic with no shading.
- Do not use faint lines and/or lettering and check that all lines and lettering within the figures are legible at final size.
- All lines should be at least 0.1 mm (0.3 pt) wide.
- Scanned line drawings and line drawings in bitmap format should have a minimum resolution of 1200 dpi.
- Vector graphics containing fonts must have the fonts embedded in the files.

Halftone Art



- Definition: Photographs, drawings, or paintings with fine shading, etc.
- If any magnification is used in the photographs, indicate this by using scale bars within the figures themselves.
- Halftones should have a minimum resolution of 300 dpi.

Combination Art



- Definition: a combination of halftone and line art, e.g., halftones containing line drawing, extensive lettering, color diagrams, etc.
- Combination artwork should have a minimum resolution of 600 dpi.

Color Art

- Color art is free of charge for online publication.
- If black and white will be shown in the print version, make sure that the main information will still be visible. Many colors are not distinguishable from one another when converted to black and white. A simple way to check this is to make a xerographic copy to see if the necessary distinctions between the different colors are still apparent.
- If the figures will be printed in black and white, do not refer to color in the captions.
- Color illustrations should be submitted as RGB (8 bits per channel).

Figure Lettering

- To add lettering, it is best to use Helvetica or Arial (sans serif fonts).
- Keep lettering consistently sized throughout your final-sized artwork, usually about 2–3 mm (8–12 pt).
- Variance of type size within an illustration should be minimal, e.g., do not use 8-pt type on an axis and 20-pt type for the axis label.
- Avoid effects such as shading, outline letters, etc.
- Do not include titles or captions within your illustrations.

Figure Numbering

- All figures are to be numbered using Arabic numerals.
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• This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Ethics Committee of University B (Date.../No. ...).

• Approval was obtained from the ethics committee of University C. The procedures used in this study adhere to the tenets of the Declaration of Helsinki.

• The questionnaire and methodology for this study was approved by the Human Research Ethics committee of the University of D (Ethics approval number: ...).

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Appendix D: SIP - Lay summary of study

Staff views on impact of COVID-19 and best practice dementia care

The pandemic placed increased demands on the NHS. Many staff members provided vital care for patients with COVID-19, continued to support others to stay well, and supported their co-workers through the difficult time. It is unsurprising that health care professionals experienced anxiety around keeping themselves and their loved ones safe. Many became unwell, suffered their own losses, and worked with huge changes and staff shortages.

For patients, being in hospital can be a difficult experience, and even more challenging for individuals with delirium or dementia as many experience increased confusion due to the unfamiliar hospital environment, staff and routine. The pandemic brought about additional challenges with new regulations for social distancing, no visitors, and the increased use of PPE. Due to these restrictions, dementia patients are at risk of becoming socially isolated, particularly as they were not having any face to face contact with relatives and group activities were not able to continue (Wang et al., 2020). During the pandemic, it is possible that staff were not able to provide the same level of care to their patients. We spent time on one of the wards in Milton Keynes University Hospital speaking to nurses and health care assistants about what their experience was like caring for dementia patients during the pandemic, and how we could help.

<u>Incidents of challenging behaviour</u>
Challenging behaviour did not seem to rise during the pandemic. The number of incidents reported were 50% lower during the pandemic than prior to the pandemic, possibly due to there being less people admitted to the hospital. In comparison, there were around the same number of incidents as to be expected given the reduction in dementia patients being admitted.

<u>Good practice care</u>
Staff recognised that when working with patients who display challenging behaviours, it is important to understand the behaviour within the context of the individual person and explore any potential causes for the behaviour such as any unmet needs (e.g. pain or hunger). Intervention should then focus on meeting that need for the patient. They also highlighted the importance of social stimulation, such as time to sit and talk with patients and activities to occupy their minds and create connection with others. This was more difficult to do during the pandemic due to social distancing and staff shortages.

Staff also stated that at times additional supports are used to support patients with challenging behaviours such as medication, security support and legal frameworks, however that these are used as a last resort after attempts to work with the patient have been exhausted.

Staff seemed to have a good awareness of the recommended guidance for supporting patients displaying challenging behaviours, however they did not discuss using the Mental Health Liaison Team for guidance, the use of distraction or relaxation techniques or considering the impact of the environment. It could be that staff are not aware of these factors that could improve patient care and reduce challenging behaviours.

Staff ability to confidently support patients

Staff confidence in supporting patients with dementia and/or delirium who display challenging behaviours did not appear to change during the pandemic when asked to rate their confidence at the time of the interview and prior to the outbreak of COVID-19. Staff felt they did have to adapt the way they worked as caring for someone with dementia and caring for someone with COVID-19 involved different support. They also needed to provide some additional support, for example helping patients to understand the pandemic and keeping themselves safe. Although they noted it was not possible to socially distance on the ward to appropriately support their patients, they felt they were unable to provide other aspects of care during this time, such as spending time talking with patients.

Staff also mentioned that the pandemic took a toll on them emotionally and physically as they experienced anxiety working in a hospital and with covid-positive patients, and those who display challenging behaviour. They stated that their workload was impossible to achieve and some staff morale was low.

The lack of relative contact was highlighted as something that had an impact on patient's health and wellbeing, as well as the care provided as some staff felt it was harder to get to know their patients, particularly those who were unable to communicate their needs. Staff mentioned that their boundaries shifted and they created a family atmosphere to accommodate for the loss of relative contact for patients.

What staff felt needed to change

The staff members reported that they would like increased support, through more visible management staff, and time to talk to someone outside of the ward when needed for emotional support. They also recognised that training and accessible written guidance would be useful, as well as increasing activities on the wards and reviewing the guidance for no relative contact. Ultimately, staff felt they needed more staff members and more time to give to patients.

Recommendations have been made and put to senior management with the hope that these can be implemented to improve care on the wards for patients with dementia and/or delirium who display challenging behaviour, both generally, and in the event of another wave of the COVID-19 pandemic, or other infectious disease outbreaks.

As a result, the service is holding additional training for staff working with patients who display challenging behaviour, and written guidance has been made available to them. They are also planning to employ a Meaningful Activities Coordinator to increase activities on the ward, and considering other means of increasing stimulation and connectedness, such as the use of an iPad to show videos, exploring singing/dancing opportunities for patients, and a text service for relatives.

The team will continue to monitor the impact of these changes on patient care and incidents of challenging behaviour on the ward.

Appendix E: SIP - People participation – agenda for meeting between researcher and collaborating carer

Experiences of care

1. For context:
    a. Does your relative display challenging behaviour?
    b. Frequency of hospital admissions
    c. Has the relative been admitted to hospital during the pandemic?
    d. Frequency of contact between carer and relative with dementia?
2. What is your understanding of challenging behaviour and how it can be effectively managed in a hospital setting?
3. What are your experiences of hospital admissions for your relative, before COVID?
4. If your relative has been in hospital during COVID-19, what was your experience then of the admission?
    a. Did you notice any differences?
5. In your experience, what was most helpful for you as the carer?
6. What do you think was most effective/helpful for your relative whilst in hospital?
7. Was there anything that was unhelpful for you or your relative?
8. What are your views on different ways of managing challenging behaviours (such as medication versus understanding vs activities etc).
9. What would you like to see in regards to your relatives care in a hospital setting during the pandemic (or other infectious disease outbreaks)?
    a. What would you like to see from staff?
    b. Was there something you found from other services that you think the hospital should also apply?
10. What do you think staff require in regards to support in order to deliver good care to your relative? (e.g. training, resources, etc).

Developing questions for staff:

11. What is your perspective of this project generally? In your opinion, what would be important for us to explore and discuss with the staff members?
12. What would you hope to gain from us speaking with the staff? What do you think our aims for this project should focus on?
13. Introduce our initial aims for the project
    a. Is there anything here that you agree/disagree with? Is there anything you think would be important to add?
14. Do you have any thoughts on what would be good questions to include? Or broad themes of questions?
15. Discuss together possible questions

Appendix F: SIP - Staff confidence questionnaire

Staff views on impact of COVID-19 and best practice dementia care

NHS Central and North West London NHS Foundation Trust

UNIVERSITY OF OXFORD

CONFIDENCE MEASURE

Please rate your confidence in the following areas:

1. **Working with patients with delirium and/or dementia**

Pre COVID-19

1 2 3 4 5 6 7 8 9 10

Little to no confidence *Very confident*

During COVID-19

1 2 3 4 5 6 7 8 9 10

Little to no confidence *Very confident*

2. **Working with patients who display challenging behaviours**

Pre COVID-19

1 2 3 4 5 6 7 8 9 10

Little to no confidence *Very confident*

During COVID-19

1 2 3 4 5 6 7 8 9 10

Little to no confidence

3. **Supporting patients when displaying challenging behaviours**

Pre COVID-19

1 2 3 4 5 6 7 8 9 10

Little to no confidence *Very confident*

During COVID-19

1 2 3 4 5 6 7 8 9 10

Little to no confidence

4. **Feeding back to my team about what may help a patient with challenging behaviour.**

Pre COVID-19

1 2 3 4 5 6 7 8 9 10

Little to no confidence *Very confident*

During COVID-19

1 2 3 4 5 6 7 8 9 10

Little to no confidence *Very confident*

Appendix G: SIP - Interview schedule

Staff views on impact of COVID-19 and best practice dementia care

Interview Schedule

1. What experience do you have of working with patients with delirium and dementia?
    a. How do you understand the differences between delirium and dementia?
    b. Have you worked with patients with a cognitive impairment whose behaviour you found challenging? If so, can you give an example.

2. What were your views on the training that you/the Health Care Assistants attended?
    a. Did you find it valuable? Which aspects?
    b. Did it impact the care you provided? How? Why?
    c. Have these changes continued?

3. What are your views on how we can effectively manage challenging behaviours for dementia patients on the ward?
    a. Who usually supports dementia patients with this whilst on the ward?
    b. How could we improve?

4. How has COVID-19 impacted the ability to attend to individuals with delirium and dementia associated challenging behaviours?
    a. What has had the biggest impact?
    b. How have your approaches changed, if at all?
    c. Has medication use increased?

5. What differences, if any, did you notice in how patients with delirium/dementia were cared for during the first wave of the COVID pandemic?
    a. How did COVID-19 impact on dementia/delirium care?
    b. How, if at all, has COVID-19 impacted on building relationships with patients and carers?
        i. E.g. communication with carers and loved ones changed at all? Impact on this on you as staff, and patients/relatives?

ii. What information are you given about patients e.g. ‘This is Me’. Has this changed during COVID-19 restrictions? If so, what has been the impact of this?

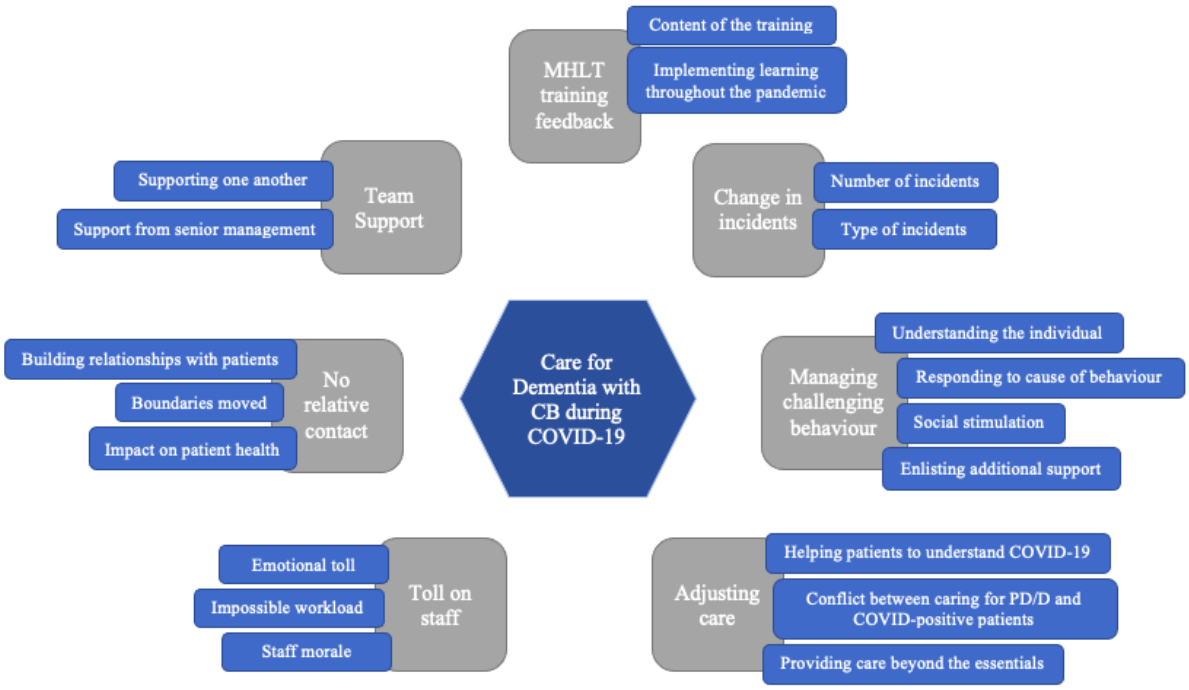
6. Have you noticed any changes regarding incidents of challenging behaviours on the wards during COVID-19?
    a. Changes in the number of incidents?
    b. Changes in the presentation of challenging behaviours?

7. What concerns do you have about working with patients with delirium/dementia and challenging behaviour in the context of a second wave of COVID-19?
    a. Has COVID-19 impacted your confidence in supporting dementia patients displaying challenging behaviours on the wards? In what way?

8. In your opinion, how can care be improved, and challenging behaviours be managed more effectively if there is a second wave?
    a. What do you consider to be ‘best practice’?
    b. Communication?

9. What would you/staff team need in order to deliver this? What would be helpful?
    a. Emotional support?
    b. Practical support?
    c. Education/training? – Based on what?
    d. New procedures/policies? – Including what?

Appendix H: SIP - Qualitative Themes



Appendix I: SIP - Additional quotes to support themes

Theme:	Subtheme	Supporting quotes
MHLT Training	Content of the training	"It was a good experience for all of us, because the thing is we've all come in from different areas of work to work on the ward and we have predominantly dementia patients, so it was very good to team build, to actually understand all together what it means. We had certain patients that were very challenging and I think this was one of the reasons why this training came up because we were coming across these very challenging behaviours, we were getting very frustrated but once we'd gone through the dementia training we were "OK, so there's a reason behind that CB, it wasn't just them being.." because some patients were coming on [to the ward] and they're not diagnosed and so of course your faced with these challenges but actually you can see - that's why the behaviour was the way it was." "The most useful was to understand that the person that you are dealing with, they could be a person talking to you, they could be your mum, your dad, or whatever, but they've got an issue that they cannot recognise themselves, you see? So you as a carer have to be aware, not always but you have to learn and study the person to understand what is happening." "Yeah because I started here last November, then the way [the staff] were saying 'we can't have this patient on the ward it's very difficult, very challenging, this is not the ward for them, [inpatient unit] is better for them, or [Older Adult inpatient ward] is better for them' but since the training they know that it is part of nursing and we need to deal with that because it's a part of the nursing caring that we do."
	Implementing learning throughout the pandemic	"You know COVID messed things up in a lot of ways. You know we had young starters from college coming and all sorts and everything just – so anything that we wanted to bring forward, we got on, we knew we had more knowledge but might not have been able to take forward everything at that time, so our knowledge was there but our appreciation of other areas that we covered probably you know, took a back step" "Yeah knowledge is wider but whether we get to use other aspects within the role, especially when we became a bit manic and you know, short staffed." "It was more difficult [to implement], as I say because having delirium and then having COVID, you're dealing with two things, it's not something that you're used to and then you've got to really know the patient to know that -OK this patient, this is how they

		used to act and now there is something else coming- so we've got to find out very quickly how to tackle it."
Change in incidents	Number of incidents	"I thought there were less, when we had big covid, but now I feel it is getting more. Well seeing now as ward is full and how half of the patients are challenging behaviour I feel like its .." "There's been no massive rise because of COVID or no decline." "[incidents have] gone down. I have to say. We are not, because obviously what is happening in the hospital we are not having as much patients that have got dementia than before, so it's, we have er, there was a week we had one that was really really, out of, it's not his fault but his behaviour was very very bad so we got one of the colleague got hit in the eye. Yeah, he had a very bad hit. But since then, we haven't had high behaviour that challenge, in the ward." "We had less [incidents] because the number of patients were less."
	Type of incidents	"We didn't have a lot on here at the time. Some of them, The ones we did have, did get a little bit worse, they did became a little bit more aggressive, they couldn't understand why we were at them with a mask." "the freedom to go or to sit, sit with others, go to the day room, sit two or three patients together and watch the TV, or just go around go to the costa coffee or to the restaurant, these all these changed but I don't think. And I don't think dementia patients when they are confused they notice if its COVID or Non COVID, behaviour the same, but staff really felt it." "the dementia and the challenging behaviour on this ward, it's always the same, always the same." "It's probably about the same, I'd say it's probably about the same, it's quite a frequent thing on here to get assaulted, and its usually the same patients so you usually clock which ones it is. So you usually know who is likely to do what."
Managing challenging behaviour	Understanding the individual	" My view is that if you understand the patient, that's the first point that will be helpful. If you understand the patient you are dealing with, you know how to tackle the situation. But if you don't understand the patient, it makes it hard. And some of them are quite abusive so therefore you can't just come straight and start communicating with the patient without finding out how to approach the patient." "I think a lot of it is just knowledge and knowing that usually this behaviour happens because they want something and if you are

		being told you can't get up and go for a walk, you are going to get more aggressive, whereas just letting them go for that walk actually solves the problem. And I think a lot of people don't always take the time to – I think there's a lot of things but I think a lot of it is knowledge and experience." "Every day is a challenge on this ward, every day. Every dementia patient is different from each other, they are not all the same, they don't all need the same level of care or same type of care, everybody is different. But, by dealing with so many dementia patients, I think we all, including me now after coming here, know how to deal with them as an individual just to see them as an individual and their needs, how they cope, because every single dementia patient's needs are different and they cope differently, so yeah. I think just individualised care actually. Some they love to sit and watch TV, some don't want to be distracted, want to be left, some want rest, they don't want to be stopped, and some they will be happy when they hear from the family"
	Responding to cause of behaviour	" Yes because even your tone of voice or your erm the way you approach, sometimes it could be that they are nervous, or they need a bit more, additional chatting to, support, you know and certainly in that particular case he would express what he wants to do, produce his hands, get up, walk, but couldn't function between the brain to the hand what he needed to do, and I think we just couldn't understand that because we could see he could get to go to the bathroom, so with him it was about talking him down and talking him through what he needed to do to see the process through without just saying 'well go to the toilet then, you know how to go to the toilet, go to the toilet' because he couldn't put the two together, so with him it was a case of talking him down you know this is what you need to do to go to the toilet, because he couldn't put it together. So you know it did help in a lot of ways with the kind of patients we were coming up against." [B] "we've got to be careful as well, if you don't know what is the main cause of the behaviour you can't just give them the medication to say 'ok we'll give them that to stop the behaviour' you have to find out first what is wrong." [C] "I mean a lot of the time you have to find out what they want because most of the time they are behaving like that because they want something. What we tend to notice on here is that, when you tend to get the ones that like to wander around, they are being told constantly to sit down, it makes them more challenging, the behaviour worse when actually they might just want to go for a walk. So I'm always very, my first port of call is find out what the problem is and if I can solve it, because sometimes they just want a cup of tea sometimes they just want to go for a walk, sometimes they just want to get – just – they just want something, and being

		told to constantly sit down and not being engaged with I think a lot of it is boredom – I mean there is not a lot here to do, that's the biggest problem we've got is there is nothing for them to do" [D] "for me, it's always talk to patient first, try and find out if there is something I can solve, it might be a cup of tea, they want to go to the toilet, they want to go for a walk, if it's something I can fix then I try my best to sort of to facilitate it so they get what they want and that usually calms them down." [D]
	Social stimulation	" Before covid we put like a table in the middle of [our] bay which is like our dementia bay I'd say because we can see it. We would put table and they would all sit down all have a meal together, we would play dominos with them, but because covid started it all kinda. Yeah." [A] " we did have activities and like books. When you are in hospital there isn't much. If someone is here for a month, if have dementia. We often see them kind of like, I don't want to say get worse but their mental health get worse because they can't see their family they can't go out for a walk, they can't sit and listen to music, they can't do activities like cooking, cleaning, anything that was occupying their mind before, because obviously activities in the hospitals are very limited." [A] "Activities, erm, you know is key, you know in some wards, ward [X] they've got a beautiful big place where they used to serve dinners and it would be great to see a ward like this moved to somewhere like that with a big room, for people to come in to because dementia patients end up just being shoved into their bays, we worry about them walking about but if we had this room that was just for people to do in and have as a day room, this [room seated in] is the day room but it's not great, you know, I think we could do with activities to stimulate, and once COVID is over, for families to be able to go in and integrate in the room too. You know because even if Joe Bloggs is sat with his daughter, his daughter could be talking to someone else, an interaction could be happening then, you know without the staff needing to be- you know, so there are possibilities and one thing I always think as well is pets, animals. And I know the hospital has been talking like [senior staff] set out about a year ago that they would bring pets in to the hospital but obviously with COVID that sort of put that to the back burner but I totally am behind that animals are a great stimulant for stress reliever." [B] "And things like the paper trolley stopped coming around so the men weren't getting their newspapers, they were wanting papers to read so then we were having to go down to the shop to buy them papers, so I think in the end we argued and they got some charity money to then pay to get some papers brought to the ward, so we

		now get papers delivered daily to the ward, which is of benefit to them to give them something to do." [D] "this social distancing also effected, majority of patients because, we used to have breakfast morning, they used to get up, dressed, come to the dayroom, we used to set up a table and sit around, you know like a family breakfast like. And we were thinking of also putting up a bus stop kind of thing in the corridor, but it cannot be done because you know the folding chairs, we can't keep a chair in there a proper chair in there because the corridors are small, patient transfer is difficult, folding chairs, if the patient goes to try and sit and the chair folds, it's dangerous so that also. Then we had a comfy corner at the end of the corridor in front of two bays, there we put, you know we just did some activities with them like you know painting, colouring and reading, playing you know the crossword and everything, this all stopped because of the COVID, social distancing." [G]
	Enlisting additional support	" Medication is always the last resort, yeah. I know some of them are very aggressive but we always try to have a verbal, talking to the person, trying to see what is wrong and you know, and if they don't respond then that's when you know the pharma(?) team, we've got to find, what medication is suitable to the behaviour." [C] " In some other cases it is now in our hands and it don't work, in that case we put patients on DOLs legal frameworks and make sure they are safe, and we do act according to their best interest, sometimes the family are involved, we call the family, during the pandemic time we can't just much help from the families because they can't visit so we do call to the phone, or we've got a special little ward phone" [E] "Well obviously if we see a patient getting upset or doing something that dangers him, we will stop doing what we are doing and make sure he's safe, come and give him support, try to bring other staff to give him support, ring the site office and say we need more support here or something. Obviously when patient getting really aggressive towards us and we try everything, we can call security to just come and sit with them, have a talk with them, chat with them, explain to them, but with dementia it's hard because it is mental health but then we can't, we can't judge them do you know what I mean, you can't…"[A] "We put a call out to security once the incident's happened to get their support so it's not escalated any further." [F]
Adjusting care	Helping patients to understand COVID-19	" I remember we had a patient in side room 2 and he was COVID positive and he was dementia and that was really difficult because obviously the oxygen, he would remove it and we were having a hard time to explain he can't remove it and things like that. Erm, we need to wear a mask, he couldn't hear us, and he would keep

		removing our mask but it's hard to explain that we can't remove our mask because, so, I felt it was more, the most difficult thing was communicating with pts with dementia who had COVID. Because it wasn't easy to explain why they are here, I remember there was also one patient in side rm 3 he didn't understand what he's got, he just didn't understand that he's got this virus he just kept saying 'what is it, what is it?' because he had no phone, he had no tele in the room, he hadn't even heard about it. So we kept reminding him and we explain to him but it was very hard to explain to them what is happening in the world now, what are the symptoms, that we can't remove our mask, it's hard because they can't hear us, they can't read our lips, it was very hard communication and everything." [A] "they couldn't understand why they couldn't leave the room, why is nobody coming in, and, I don't know. Obviously we were advised to come into side rooms less times that we can because it wasn't safe for us, and I would come and do everything and say 'do you want something?' and he would say 'no no no leave me alone, I'm ok' and then as soon as I walked out he would buzz the buzzer and I would have to dress again, come in for him to ask me 'oh what's the time?' do you know what I mean, it was very hard to explain that we can't have that normal contact all the time because he had to isolate himself." [A]
	Conflict between caring for PD/D and COVID-positive patients	" we didn't really pay much attention to the rest of the ward at that time, because we were so busy with the COVID patients" [B] "Because if you have someone who has, got problem with respiratory, because with COVID that's what they do, high temperature. You, not only thinking I need to make sure that person is safe, and you have to respond very fast and quick. When, if it is dementia it's a different approach with to tackle the patient, so having COVID on the ward makes life very difficult." [C] "they forgot they were dementia patients. It was 'Its COVID' – they forgot the underlying dementia side to them." [F]
	Providing care beyond the essentials	" It's very difficult because we just can't, there is obviously things that the ward needs to be doing like breakfast, meds rounds, washes and everything and then in middle of that if the dementia patients require something else, we just sometimes cant, sometimes find it hard to provide it. Talk or, go for a walk with them or sit and play music with them, it's very very hard." [A] "I mean like, just any patient – the amount of time it takes to brush their hair, wash teeth, shave they are luxuries. And it's sad to say but they are luxuries because you're on to the next- on to the next – on to the next. So, dementia patient you know- and if we are rushing, they're stressed, they can probably feel our stress and so it's not a nice relaxed ambience for them." [B]

		"yeah because you've got that distance, you couldn't have that contact, you couldn't get to know that patient, everything had to be done at a distance, it was a case of, you go in, get done what you needed to do, and come away." [F] "Then, our work load too to be honest because we can't spend more time with them, what they really need to keep them engaged, to spend time with them. Staffing, during COVID, I had quite a few staff off sick and erm, we couldn't provide that much time to spend with them so, everything. That's what I feel." [G]
Toll on staff	Emotional toll on staff	"…you know if someone coughs next to you, you think 'oh my word, this person is not feeling well' you know or am I going to catch it or how is it going to be. But then you are frontline you have to help, you can't just sit there and say oh I'm not going to touch the person, you see?" [C] "..you don't come to work to be hit, kicked, thumped, but you know they can't help it, but you still need a bit of support there for yourselves." [F] "I don't completely work in covid wards, I know many of them are completely covid, but I've been there a couple of times because they were short of staff and I'm so scared there honestly, I know I will get it, but I will be alright but, I got it very badly and I'm still unsure where I got it but that time I only wear my apron, like a personal care apron and my mask. And I feel like, you know we are going to a big war without any weapon you know, just in front line just ready to get it, hit it." [E] "…the abuse we got off relatives on the phone was not fair to the staff either – having to explain to the relatives that they couldn't come in because it was trust policy. And then they'd be getting 'yeah but, why can't-'. Or you get like someone who was dying on end of life who would get one visitor and then you'd get another patient going to me 'well why can't I have a visitor' and you'd have to try to explain that they were dying without trying to tell them. It wasn't very pleasant. Being stuck constantly in the middle with all of these people." [D]
	Impossible workload	" And the phone calls on this ward in particularly were so high we got so many complaints because we couldn't actually answer the phones because the phone never stopped ringing." [D] "they put all expectations in you and then moan that we are not doing anything, but it's actually in reality when you look at what we actually have to do, it's impossible to achieve. And, people don't do things because we haven't got time. We don't have time. I mean I'm surprised I have been able to sit in here for however long without being interrupted. That's why I told them not to tell

		anybody where I was, because I can't even go to the toilet without someone harassing me." [D]
	Staff morale	" They are not things that are going to change overnight across any hospital, it's always going to be the same, Its going to be staffing and it's going to be time and I just don't think either of those are achievable, sadly." [B] "I probably don't any real concerns personally because I don't think much will change" [D] "Staff morale is a big big issue. When you try and say something your told you've just 'got to get on with it', but it doesn't help you mentally when that's what you are told all the time. And you need people that understand that we've got families. I've, My grandson was born during covid, I could not go and see him. But if they'd have said 'oh we'll just keep you off the COVID wards' then you know, my chances of being able to of seen him would of been, you know, but there's just no one standing, you know, it's very much oh its COVID, it's an issue, just get on with it. It's nothing in the individuals impact of working with them" [F]
No relative contact	Building relationships with patients	" The only thing I'd say is that possibly, how you approach or look after a dementia patient, sometimes you are better judged by having met the family members, or seeing family members with them, seeing what it is that makes them suddenly talk, suddenly smile, because they could look miserable as sin with you and then their family walks in – so those sort of things are missed, because you can't read what their behaviour is because it's very different to how it is with family members." [B] "Because before we had the COVID we used to have visitors and either the wife or the daughter would tell you what they like. Even when we are giving them care, they would say 'ok can I tell you how they like to be approached or what we do' yeah that was good yeah… During COVID you can't have that because there is no one coming in, the only person you've got to deal with is the patient sitting in front of you and then if they are aware you can get some information from them, but if they are not aware you can't have it, you see?" [C] "I think it was harder to get to know the patient because you couldn't just ask the relative what they like what they didn't like, doing menus and things was more challenging because not everyone can tell you what they like." [D] "I Found it horrible. You couldn't sit with your patient, sit and hold their hand and just talk. That was stopped. I found that very very hard." [F]
	Boundaries moved	" Oh it wasn't good. Because I put myself in their shoes if I was in the hospital I would love to have my loved one to visit me, to

		make me comfortable you see. We become like a sister, brother, daughter, relative to them. We've got to take that place and talk to them and make them happy, sometimes they are very sad they cry and we have to make them, you know, comfort them and say no don't worry, they are coming to see you soon." [C] "Everything has changed, because we know that they can't have their family members, it's very very important to them, and to the families too. Our approach and the work style, everything changed because you know we need to Update the family every day, we make sure, if they can, they want to speak to the family we need to do the facetime, so we have to prepare them for the facetime because you know, they need to have iPhone there, phone, and er we, whatever happens now, it's a confidentiality challenge, patient confidentiality. We never used to discuss about patient issues, more than what we need to, sometimes we have to if we need to if we inform the next of kin because there is no other way to let the family know how they are, what we are doing with them." [G] … I think the policy is still the same from covid, I haven't heard anything like our policy has changed, still we are only allowed to give Basic information but you can see that they, the relatives, they are expecting more through the phone and sometimes, erm we have to explain more, sometimes we have to kick that boundary line a little bit further and had to pass a little bit more information to make sure the family.. Because I am thinking if my parents are in the hospital I am expecting more because I can't go to the hospital." [E] "Nurses need to be empathetic anyway I don't think that, but it's more of an attachment than, because always say that nurses shouldn't be close, you know attached to patients and we've got boundaries, but I think we've kind of broken those boundaries a bit because it is only them and us. We and patients, so, we just we sing for their birthdays, and we are not allowed fresh flowers so we kind of bought cards and small gifts, piece of cake and we celebrated, we sang, and some of the staff they danced in front of them so that role, we started doing more, we always did it but kind of did more of-" [G]
	Impact on patient health	" I think that not having visitors was detrimental to a lot of these patients because a lot of them want to go and see their husband, go and see their wife, its usually wives and daughters, and you are trying to tell them that they can't and when you they can't do it, they get aggressive, but I can't do it, it made it, the violence got worse because we couldn't facilitate what they wanted. And then when you tried to get visits it had to go through the matron, then it had to go up to gold and then you'd get like one hour, which is never – I don't think it was well thought I think for wards like this the risk should have been weighed up against the benefits for the patient, rather than judging the whole hospital as a whole. I know

		that's a harsh thing to say but I think somewhere like this, we should of have that visiting, even if we had a booking system, I think it would have been better for them because the detrimental impact on them was phenomenal, when people were going back home they were obviously having bigger deliriums because they weren't seeing – then they were bouncing back in, it all just.." [D] "Well they were seeing their relatives at home but by the time they got home after two or three weeks, half of them don't remember who anybody is do they because they forget people." [D] "Challenging behaviours, because they are so used to seeing their family members or visitors or, and all of a sudden they come to hospital and they are not allowed to come, and they see us, entirely different, because to be honest, I think background also based in here because most of our nurses are like, not English nurses on the ward, because they are from the generation mostly they are all very, British families like, they see all their own people around then they come to see us and sometimes they feel like "Am I in my own country? or" it's a bit confusing" [G]
Team support	Supporting one another	" well during the – in terms of emotional support – um. there isn't, there isn't much, do you know what I mean, we have our matron or our managers, we can speak to them but we didn't have that group support or anything like that, I don't even know whose organising that or if they would but they always know if I'm having a bad time or a hard time I could speak to my manager let them know how I feel and in the team we always talk to each other and kind of, if someone is feeling more emotionally drained we will try to lift them up so we kind of like, in the team, with our managers and ourselves." [A]
	Support from senior management	" I don't think we look after ourselves or look after each other well. I think I try my hardest to look after them but, it would be nice if the seniors stepped up and actually started to come in onto this ward and doing shifts with us and seeing what it's like. That's what I would want. [D] "of course, we enlist support like from Medical Divisions teams, they give lots of support, even though I haven't actively particular training from the specialist teams recently, but I always check with them, even today, someone [name] from the medical divisions team came to see one of our patients who has got dementia, psychiatric issues, we always check with them when they come if we need to do any different way of handling the patient you know things like that. So personally I would say, probably because handling of care we are all focusing that way, I can't, I can't see any big difference but that staff are doing a really good job. Especially, almost, always 90% of staff are permanent you know, new starters shadow staff normally so they always watch and see what we are doing, and if someone are more experienced and they move there are always staff there, so you know it's always a cycle

		isn't it, so we always support our staff and we support each other. So that may be helping at the moment." [E] "of course, we enlist support like from Medical Divisions teams, they give lots of support, even though I haven't actively particular training from the specialist teams recently, but I always check with them, even today, someone [name] from the medical divisions team came to see one of our patients who has got dementia, psychiatric issues, we always check with them when they come if we need to do any different way of handling the patient you know things like that. So personally I would say, probably because handling of care we are all focusing that way, I can't, I can't see any big difference but that staff are doing a really good job. Especially, almost, always 90% of staff are permanent you know, new starters shadow staff normally so they always watch and see what we are doing, and if someone are more experienced and they move there are always staff there, so you know it's always a cycle isn't it, so we always support our staff and we support each other. So that may be helping at the moment." [F]

Appendix J: SIP - Additional quotes to support recommendations suggested by participants (RQ5)

Training and guidance	Benefit of training	"Yeah I would like to include in the training that if we get a patient who have dementia, we have to be trained how to pick it up, first of all, and then secondly how to detect whether they will be violent in their behaviour or not, because not all of them are violent, not all of them. So we have to be trained to tell whether a patient will be violent. They've got dementia, are they violent, what makes it trigger, what time of the day could they start? Because sometimes as I say, they could be good in the morning, going towards the afternoon something just happened." [C] "Does it really change anything, you can put all these policies in place, all this guidance but does it really change anything if people don't have the training to do that? You need to start off with that basic training and then bring in policies and guidance afterwards. There is no point having them if no one has been trained how to do it." [F]
	Written accessible guidance	**"**To be honest I haven't seen anything [guidance/policies] to tell you how to manage, you have to use your brain and see how to approach and manage the patient." [C] **"**The main problem that we faced, we, staff on the ward, we thought 'oh my god If covid comes to the ward' my friend is working in different NHS trusts around the UK and I always communicate with them and I always think I need some help because, there is no protocol in place when what you are trying to do, so it was something like that so, all the wards are getting the you know– covid patients, and if a covid positive comes to my ward and I can see that they are confused, Dementia patients, with dementia you know so they all walk around, running around, and what will happen to us?" [E] "that is a strange time you know, nobody knows much what to do but we just make sure everybody is safe." [E] "I was being not told off but prewarned about something no one even told us about, and the rules was changed during the night and no one would actually tell the wards about it. Do you know what I mean, they would decide in the offices, do you know what I mean and no one actually notified the ward. So it was, I don't know it was very, just a big question mark" [A] "[we need] written information about what we need to do as I'm saying we would get the PPE, it was put on the ward, then in the

		morning we would come it was taken off and something new." [A]
Social stimulation	Relative contact	"Well I would definitely say, if there is a way, then they should leave relatives to come in and see their loved one, because that does help, so I don't know why they are not letting them come, I do understand that they say if they come in they might bring the virus in, but when they are at that level all they want is to have someone that will reassure them that the used to, because they are not used to us, they could be here for months but it's still not the same." [C] "I think for me if I could change anything I would want visiting is what I would – I would insist that they change, they made a ruling for wards like ours that we could have visitors in because for me that's what - it caused the biggest detriment to these people" [D] "most of the time because you know when [staff] are busy, the 'wanderers' will come and sit [in the office], I'd give them some chocolate, and I do my work and they sit [in my office], make a cup of coffee, tea, chatting to them and doing my job, so I did that since a year, and even one of the patients today keep coming behind me … but you know if the families are there at least in the afternoon they sit with them and staff can concentrate on what they [need to do]. It's all changed, but the care has not been compromised, that is for sure." [G]
	Stimulating activities	"if we had this room that was just for people to do in and have as a day room, this [room seated in] is the day room but it's not great, you know, I think we could do with activities to stimulate, and once COVID is over, for families to be able to go in and integrate in the room too. You know because even if Joe Bloggs is sat with his daughter, his daughter could be talking to someone else, an interaction could be happening then, you know without the staff needing to be- you know, so there are possibilities and one thing I always think as well is pets, animals. And I know the hospital has been talking like [senior staff] set out about a year ago that they would bring pets in to the hospital but obviously with COVID that sort of put that to the back burner but I totally am behind that animals are a great stimulant for stress reliever." [B] "maybe the freedom to go or to sit with others, go to the day room, sit two or three patients together and watch the TV, or just go around go to the costa coffee or to the restaurant, all these changed" [G] "Because my background is nursing I worked in a nursing home, we had an Activity coordinator which really helped because they used to take them out sometimes, and they used to take them out to the garden, we used to play with them, we used to have

		singers, they sing for them. Choir during the Christmas. So that was really keeping them really entertained. So I did ask matron and that plan started but because HCAs who know the ward wanted to play a role, and then they couldn't fund it so it is still on a request because we had a fantastic activities coordinator, used to take them out, with some of the HCAs and for tea in the evening, it was a bit of entertainment for them, a change of scene." [G]
	Resources	**"**It's very difficult because we just can't, there is obviously things that the ward needs to be doing like breakfast, meds rounds, washes and everything and then in middle of that if the dementia patients require something else, we just sometimes cant, sometimes find it hard to provide it. Talk or, go for a walk with them or sit and play music with them, it's very very hard." [A] **"**dream world that would be, if we got a second wave we would like to see additional help, not nurses necessarily but HCAs or even support staff, someone to make the teas do more tea rounds, or erm, help with erm, I don't know, stocking up the cupboards – those things take up a lot of time, so you know and if you are running behind with time those are things that would need help with. "[B] **"**we need emotional support as well because sometimes we take care of the patient and if we are close to the patient, you feel for that person, then when you get home and kind of fear that 'oh my word what could I have done to make it better?' you see? So we need that as well as the patient need that." [C]

Appendix K: SIP - Service Improvement Report with recommendations

Oxford Institute of Clinical Psychology Training
Eloise Ainger
Dr Helen Cressey

NHS Central and North West London NHS Foundation Trust

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Staff views on impact of COVID-19 and best practice dementia care

The pandemic has led to increased demands on the NHS and hospital. Many staff members have provided vital care for patients with COVID-19, continued to support others to stay well, and supported their co-workers through a difficult time. It is unsurprising that health care professionals experienced anxiety about keeping themselves and their loved ones safe. Many became unwell, suffered their own losses, and worked with huge staff shortages and frequent changes.

Best practice dementia care includes individualised biopsychosocial formulation as well as person-centred preventative methods. Formulations should attempt to understand the behaviour within the context of the individual person and explore any potential causes such as any unmet needs. Intervention should then focus on meeting that need for the patient (James & Moniz-Cook, 2018).

For dementia patients particularly, being in hospital brings additional challenges. For example, the change in environment and presence of unfamiliar people, often that changes daily, in addition to their physical health difficulties are likely to lead to psychological and behavioural symptoms such as increased confusion and associated aggression, agitation, "wandering" (Kales et al., 2015; Lyketsos et al., 2014) and mood changes such as anxiety, depression, hallucinations and delusions (Finkel, Coste e Silva, Cohen, Miller & Satorius, 1996). Delirium, which can complicate the presentation of dementia, may be more prevalent during the current climate as it is caused by hypoxia, a symptom of COVID-19 (Marcantonio, 2017).

Due to distancing restrictions, dementia patients are at risk of becoming socially isolated, particularly as they were not having any face to face contact with relatives and group activities were not able to continue (Wang et al., 2020). During the pandemic, it is possible that staff were not able to provide the same level of care to their patients.

We spent time on ward 18 speaking to nurses and health care assistants about what their experience was like caring for dementia patients during the pandemic, what they felt they needed during this time, and how we should best support these individuals during such difficult times.

This report is a summary of the information gathered and staff recommendations.

Oxford Institute of Clinical Psychology Training
Eloise Ainger
Dr Helen Cressey

NHS
Central and
North West London
NHS Foundation Trust

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Recommendations based on staff interviews

As you know, we have been speaking to staff on Ward [X] about their experiences of providing care to patients with dementia who may display challenging behaviour, during the first wave of COVID-19. We were keen to hear their thoughts on whether they felt anything could have been different, or if they would find anything additional helpful in the event of a second wave.

We also asked HCAs about their experiences of the MHHLT hosted Managing Challenging Behaviour training they attended. Staff reported that the training helped increase understanding of patients and behaviours, and developed strategies that can make a difference for these patients. Some felt, understandably, that it was difficult to implement the strategies during COVID-19 due to staff shortages and need for patient social distancing.

Given that recommendations are now urgently required as we manage the second wave of COVID-19 in hospital, this brief report will focus mainly on the difficulties during the COVID period, and related recommendations.

Guidance

Staff members reported that they were unaware of any guidance in managing challenging behaviours, or supporting dementia patients in hospital, in the context of COVID. Some explained that finding guidance/policies is difficult, and time consuming. One expressed concern around supporting a dementia patient, who may tend to wander, with COVID-19, and felt there should be guidance to support them make these decisions on the ward. Although staff were generally aware of the majority of NICE guidance, some aspects were not discussed

Recommendation:

- *Encourage use of behavioural analysis (ABC) charts as a tool to understand the function of the behaviours and find realistic alternatives to prevent escalation.*
- *Make policies/guidance more accessible to staff. For example, summarise the information and disseminate in team meetings/emails/other means that works for you as a ward.*
- *Encourage members of staff to express any concerns to the Ward Manager*
- *Ward Manager to liaise with senior management to gain clarity on issues raised by staff, such as what to do in the case of a dementia patient contracting COVID-19.*
- *NICE guidance presented to staff in accessible way that can be referred back to. Posters displayed in staff areas may be most useful.*

Resources

Staff reported that during the first wave of COVID-19, due to high staff sickness rates, they did not feel they had the staffing or time to attend to individuals, that care was rushed and

stressful. They reported that spending time sitting and talking with patients can make a "big difference" to them, however they did not have the time to do this during COVID-19.

Recommendation:

- *Where possible, additional support should be provided to the staff team, and provisions to ensure risk of contracting COVID-19 is minimised for staff. This includes the accessibility of PPE that was missing when COVID-19 initially began. Staff were clear that access to PPE has been fine since, and guidelines became clearer as time went on.*
- *A couple of members of staff felt that either one additional member of staff to sit with patients and provide that social contact, or additional support for things such as tea rounds or stocking the cupboards which can take up time. We appreciate this may not be possible due to staffing levels, however it would be helpful, if possible, for existing staff to be allocated time within their duties to provide social contact and activities for patients, or for volunteers to provide this support.*

Activity

Staff reported that there is a lack of stimulation for patients on the ward, particularly during COVID-19 as group activities were no longer possible. This increased likelihood of challenging behaviour, as they were unable to occupy their time. This was exacerbated by not having any time with relatives.

Recommendation:

- *Where possible, COVID safe, individual activities could be provided for patients on the ward. These should be deemed as safe for patients who display physical aggression.*
- *In a similar manner to the relative letters (FamilyLine), appropriate activities could be provided by family members to the hospital to make COVID safe and then passed onto the ward.*
- *One staff member suggested 1:1 activities so social distancing can be maintained.*
- *Activities may reflect what the patients used to enjoy at home, such as drawing, playing cards, or puzzles.*
- *To consider additional activities that coud be restarted or introduced once government restrictions have been lifted, e.g. through an Activities Coordinator.*

Contact with relatives

This was a frequent theme in discussions with staff members. As patients were no longer able to see their loved ones, patient confusion increased being around unfamiliar faces and challenging behaviour was impacted as staff were unable to facilitate these visits.

Although an iPad was provided to support contact with family, staff reported that they had not received any training or guidance in how to do this, and therefore it was not used. Staff reported that not being able to see their relatives meant patients with dementia deteriorated

and found it difficult to recognise their families on discharge. They wondered if, as a result, the patients took longer to recover and were more likely to return to hospital.

As a result of not being able to facilitate visitors, a large amount of staff time was spent answering a huge volume of calls from loved ones asking for information regarding their relative, and receiving complaints.

Lack of relatives visiting has also meant that staff have not always been able to get to know their patients in the same way. They described not having as much of a sense of who that patient was with their loved ones, their likes/dislikes or preferences. This impacted the relationships built, as well as decisions made on their behalf such as food choices.

Recommendation:

- *Staff should be provided with training/guidance in how to operate the iPad to allow relatives to have video calls with their loved ones.*
- *Adapt communication channels with patient's families such as daily emails/texts. This could reduce the number of phone calls whilst increasing relative confidence and knowledge of the care their family member is receiving.*
- *As staff were finding the number of telephone calls from relatives overwhelming, and therefore were not able to gather as much information about their patients as they would have liked, encourage relatives to complete a 'This is Me' or equivalent to send into the hospital for staff to refer to. Staff to use 'This is Me' with the patient themselves where possible to ensure their voices are heard.*
- *Discuss if it might be possible to allow some relatives time with their loved ones, if required outside of the ward/hospital and in keeping with the government guidelines. One staff member suggested a visitor rota system.*

Staff support

Staff understandably reported anxiety initially working with COVID patients. Whilst some stated this improved over time and they have become more confident, some reported that anxiety is still very much present, particularly working with dementia patients given the challenging behaviour and confusion around the current pandemic. Staff expressed concerns for their safety and the teams' skill base to work with certain patients.

"We don't want to come to work and be treated the way we are, and no one seems to care unless something goes wrong".

Staff felt that whilst the management on the ward was good, they did not receive the emotional support they needed.

Many felt more training would be of benefit, and that this should be made mandatory to ensure strategies on the ward are consistent for patients.

Recommendation:

- *Staff management to provide a confidential space to discuss concerns with staff members and make appropriate adjustments/support where needed.*

- *Emotional support provided by someone external to the ward.*
  One member of staff felt that someone in this capacity visiting the ward would be of benefit, however that it would be important this person had a good understanding of working with dementia patients.
- *Team reflection – perhaps split into a few sessions so members of staff are able to attend around shifts. This could be scheduled for after COVID-19's second wave has ended, if it is difficult to find time to fit this in. It might be helpful for staff members to share their experiences of working during this time and strengthen the support network whilst at work.*
  - *Perhaps a part of this could focus on how we can look after ourselves and our team, as one member mentioned they felt this was lacking.*
  - *Another aspect could be sharing experiences of how they have navigated challenging conversations such as explaining the pandemic to their patients.*
- *Mandatory training for HCAs, Nurses and Matron. To be followed up to help with the implementation of ideas.*
  - *One suggestion was for this to include how to approach the patient during the challenging behaviour, as well as preventative strategies.*
  - *One member of staff suggested that a support guide or toolkit would be helpful for staff in managing challenging behaviour.*

Appendix L: SIP - Poster for staff outlining the guidance for supporting dementia patients during the pandemic

CARING FOR DEMENTIA PATIENTS DURING COVID-19

NHS Central and North West London NHS Foundation Trust

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NHS England recommendations for supporting patient wellbeing:

- Support patients to **stay connected** to others - e.g. video calls to relatives
- Be **alert to signs and symptoms of COVID-19**, which can be atypical in older people. These include loss of smell, loss of appetite, diarrhoea, breathlessness, raised temperature and cough, delirium, conjunctivitis, changes in behaviour, and falls.
- Consider different **communication methods** to support COVID identification.
- People with dementia may have difficulty understanding complex instructions or the reason for isolating/social distancing. **Personalised care plans** should include **approaches that can be used to help manage symptoms**.
- Use guidance from British Geriatrics Society to support with **managing and preventing delirium**, which can increase risk of cross-contamination.
- Due to increased challenges communicating with patients with PPE, **tone of voice, open body language and non-verbal communication such as written materials** should be considered.
- Promote overall wellbeing through **activities**. E.g. listening to music can reduce anxiety and depression.
- Ensure **needs of people with dementia are met at end of life** (Ensure needs and preferences taken into consideration, advanced care plans, mental capacity assessments where appropriate and palliative care).

***Royal College of Psychiatry recommendations for best practice care*:**

- Individuals with dementia may experience increased levels of anxiety. Time should be allocated to **complete a holistic assessment** and identify whether an **advance care plan** or a **health or welfare power of attorney** is in place.
- Complete a **swallowing assessment** if necessary.
- Ensure all **information about personal care and support for preventing COVID-19** (e.g. self-isolation, hand washing) is available in **accessible formats** to ensure the patient can access it.
- As patients with dementia and/or delirium may be less able to report symptoms, **clinicians should be alert to signs as well as symptoms of COVID-19**.
- Where required, **conversations about end-of-life care should be tailored to reflect expectations**, and **palliative comfort measures** offered.
- If a patient with dementia and COVID-19 is imminently close to dying and has symptoms such as **breathlessness or severe delirium** that are difficult to manage, **specialist palliative care support and advice should be sought.**
- See **The Mental Capacity Act (2005)** for guidance on assessment of capacity and compliance with legal guidance to act in the patient's best interest where appropriate.

Appendix M: Poster with NICE Guidance (2015) summarised

CARING FOR PATIENTS DISPLAYING CHALLENGING BEHAVIOUR IN HOSPITAL (1)

A summary of the NICE guidelines:
[NG10] Violence and Aggression: Short term management in mental health, health, and community settings

- **Staff training** in psychosocial methods to avoid the use of restrictive interventions. This training should focus on:
  - **Person-centred, values-based** approach to care
  - Understanding the **link between mental health and challenging** behaviour
  - Assessing/understanding **reasons for challenging behaviour**: "personal, constitutional, mental, physical, environmental, social, communicational, functional, behavioural".
  - Skills in **reducing and defusing** imminent aggression
  - Skills to undertake **restrictive interventions safely** when needed
  - Skills in **debriefing** following an incident and undertaking **post-incident review** with service users.
- Use of a **Restrictive Intervention Reduction Programme**: addressing environmental factors, involve and empower patients, include meaningful leisure activities, de-escalation, risk management, outcome monitoring etc.
- Staff to work as a **therapeutic team**, maintaining **staff emotion regulation** and **self-management**, and encourage **good leadership.**
- Patients to be offered appropriate **psychological therapies, physical activities, leisure activities, and support for communication** difficulties.
- **Recognise potential bullying/unwanted contact or conflicts** between patients.

CARING FOR PATIENTS DISPLAYING CHALLENGING BEHAVIOUR IN HOSPITAL (2)

- **Use knowledge of the individual** to consider how it might impact on challenging behaviour (e.g. diagnoses, current symptoms, past history) as well as the impact of being in a restricted environment, restricting a person's liberty and freedom of movement.
- Address **physical environment**al factors.
- Understand and **manage any personal factors** outside of hospital that may impact behaviour (e.g. family difficulties, financial worries etc.)
- Set out **prevention strategies** to improve quality of life, meet needs, and support emotions/symptoms leading to challenging behaviour.
- Staff **training in de-escalation** techniques: recognising signs, understanding causes, use techniques for distraction, calming, and encouraging relaxation, responding in measured way.
- Use **outcome measures** as well as unstructured clinical judgement to monitor and reduce incidents (including **risk assessment**).
- **PRN medication with a clear rationale and circumstances** to be used, not to be given indiscrimination, or routinely. Should be tailored to individual and discussed with them where possible (see guidelines for more information about use of PRN medication).
- Build a **good working relationship** with patients early in their admission and monitor any changes in mood that may lead to challenging behaviour.
- Use range of **verbal and non-verbal skills and interactional techniques** to avoid or manage 'flashpoint situations'.
- Explore **triggers and early warning signs** with patients where possible and negotiate their wishes should they become agitated.

Appendix N: SIP – Journal submission guidelines

Submission requirements

Exclusive submission to *Ageing & Society*

- Submission of the article to *Ageing & Society* is taken to imply that it has not been published elsewhere nor is it being considered for publication elsewhere. Authors are required to confirm on submitting their manuscript that it is not published, in press, or submitted elsewhere.

- If the submitted manuscript is based on a working paper (or similar draft document published either online or in print), the working paper should be acknowledged in the manuscript that the author is submitting to our journal. Submissions that are identical to a working paper or are similar to a document published online will not be accepted for publication in *Ageing & Society*.

Appropriateness for *Ageing & Society*

- All submissions must fall within the remit of the Journal, as described at the beginning of this document (i.e. the aims and scope).

- Authors should bear in mind that social gerontology is an interdisciplinary field so care must be taken to draw out the implications of the analysis for readers that may not share the disciplinary background of the author.

- The international nature of the readership of this Journal should also be kept in mind when crafting manuscripts for submission. Information on the country-specific-context upon which the study was designed may be needed for readers in other regions to appreciate the relevance of the work.

- The stereotypical presentation of individuals or social groupings, including the use of ageist language, must be avoided. Thus, for example, words such as elderly, elders, the aged should be avoided. Please consult the following guidelines if uncertain as to what constitutes ageist language:
  - https://apastyle.apa.org/style-grammar-guidelines/bias-free-language/age
  - https://cdn.who.int/media/docs/default-source/ageing/quick-guide-to-avoid-ageism-in-communication

- All manuscripts must meet the submission requirements set out in this document, closely following the instructions in the 'Preparation of manuscripts', 'Citation of references' and 'Table and Figures' sections below.

Preparing your materials

Ageing & Society is an interdisciplinary and international journal devoted to advancing the understanding of ageing and the circumstances of older people in their socio-economic and cultural contexts. Committed to publishing original and high-quality research papers that substantially contribute to ongoing debates in social gerontology. *Ageing & Society* welcomes submissions using different theoretical and methodological approaches as long as they aim to advance research, policy and practice and encourage the exchange of ideas across the broad audience of multidisciplinary academics and practitioners working in the field of ageing. Please note that due to the number of submissions we receive every year, we are unable to offer pre-screening services. We encourage you, however, to read the instructions to authors carefully.

Article Categories | **Submission Requirements** | **Preparation of manuscript** | **Preparing your manuscript for peer review** | **Ethical considerations** | **Declaration of funding** | **Conflicts of interest declaration** | **Citations of references** | **Tables and figures** | **Supplementary Materials** | **Preparing your documents for submission** | **Author affiliations** | **ORCID** | **Seeking permission to use copyrighted material**

Article categories

Articles

Articles that report on empirical research in order to substantially contribute to ongoing debates in social gerontology must contain between 6,000 and 8,000 words (excl. the title page, abstract, keywords, reference list and any supplementary material). Most papers usually have the following sections in sequence:

- Title page
- Abstract
- Keywords
- Main text (which is often comprised of the following sections):
  - Introduction
  - Literature Review
  - *If applicable,* Theoretical Framework
  - Methods
  - Results/ Findings
  - Discussion/ Conclusion and
  - *If applicable,* Implications for Policy and/or Practice
- Statement of ethical approval as appropriate
- Statement of funding
- Declaration of contribution of authors
- Statement of conflict of interest
- Acknowledgements
- Notes
- References
- Supplementary material (where applicable) – this is not included in the word limit and will be published online only.

Authors have the flexibility to organise the main text of their manuscripts into the format that best suits the topic under consideration but all of the information alluded to above should be included. Please make note of the guidelines offered under the headings 'Appropriateness for *Ageing & Society*' and 'Preparation of manuscript' since they offer more detailed information about some of these sections. Note also that the Journal accepts manuscripts that rely on different methodological approaches, as well as conceptual and theoretical contributions. The later may be appropriate as Forum article submissions so consult that section below.

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Review articles

Ageing & Society welcomes submissions of state-of-the-art review articles (e.g. systematic and scoping reviews). This type of submission should not exceed the 8, 000 word limit (excl. the title page, abstract, keywords and reference list). The following article is a good example of a systematic review published in this journal: https://www.cambridge.org/core/journals/ageing-and-society/article/coresearch-with-older-people-a-systematic-literature-review/45F60ECFDA8CEBDEECB4D841328BE728

Worth noting is also that *Ageing & Society* is – as stated in the journal's aims and scope - an interdisciplinary journal devoted to advancing the understanding of ageing and the circumstances of older people in their socio-economic and cultural contexts. We publish original and high-quality research papers that substantially contribute to ongoing debates in social gerontology. Thus, before submitting a review paper to our journal, please note that we do not cater primarily to the health/ medical and/or clinical sciences even if we recommend that authors contemplating the submission of a review article should have insight into different review types, and the fact that some review articles cater to those disciplinary traditions. For more insight into different types of review methodology see: Heyn, PC., Meeks, S., & Pruchno, R. (2019). Methodological guidance for a quality review article. The Gerontologist, 59(2), 197-201. doi: 10.1093/geront/gny123.

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Forum articles

In addition to research and review articles, we welcome critical/reflective commentaries on research, policy, theory or methods relevant to the Journal's readers. These commentaries are not appropriate for the presentation of empirical research results even though they could be informed by the submitting authors' previous research. Sometimes these articles reflect the viewpoint of the author(s) who have submitted the paper, while other times these are theoretical and/or conceptual contributions that aim to ignite ongoing debates in the field of social gerontology. Because of the critical/ reflective/ theoretical and/or conceptual nature of these submissions, it is important that authors take into account the opinions of scholars, practitioners and/ or policy makers that may disagree with the thesis/ viewpoint expressed in their Forum submissions. Please note also that Forum articles undergo the anonymous peer-review process just as all submissions to our journal do. Worth mentioning is that because our journal caters to an international audience, authors should not assume that the reader has the country-specific knowledge to fully understand the thesis/viewpoint expressed. There should therefore be enough background/ context information in a Forum manuscript to allow readers to understand why the commentary is necessary. Papers submitted for consideration as a forum article should contain 2,000-5,000 words (incl. abstracts and reference list).

Book review articles

The Journal welcomes also book reviews, which offer our readers an opportunity to become acquainted with recently published books in the field. Because the Journal's aims, among others, to encourage the exchange of ideas across the broad audience of multidisciplinary academics and practitioners working in the field of ageing, it is important that book reviews are constructed with our readership in mind. Please note also that educators in the field of ageing tend to read book reviews when searching for potential contributions to their courses' syllabus so authors for book reviews are encouraged to keep this in mind. Please make also note of the guidelines you will receive from our book review editors once you have committed yourself to reviewing a book for us.

Submission requirements

Exclusive submission to *Ageing & Society*

- Submission of the article to *Ageing & Society* is taken to imply that it has not been published elsewhere nor is it being considered for publication elsewhere. Authors are required to confirm on submitting their manuscript that it is not published, in press, or submitted elsewhere.

- If the submitted manuscript is based on a working paper (or similar draft document published either online or in print), the working paper should be acknowledged in the manuscript that the author is submitting to our journal. Submissions that are identical to a working paper or are similar to a document published online will not be accepted for publication in *Ageing & Society*.

Appropriateness for *Ageing & Society*

- All submissions must fall within the remit of the Journal, as described at the beginning of this document (i.e. the aims and scope).

- Authors should bear in mind that social gerontology is an interdisciplinary field so care must be taken to draw out the implications of the analysis for readers that may not share the disciplinary background of the author.

- The international nature of the readership of this Journal should also be kept in mind when crafting manuscripts for submission. Information on the country-specific-context upon which the study was designed may be needed for readers in other regions to appreciate the relevance of the work.

- The stereotypical presentation of individuals or social groupings, including the use of ageist language, must be avoided. Thus, for example, words such as elderly, elders, the aged should be avoided. Please consult the following guidelines if uncertain as to what constitutes ageist language:
  - https://apastyle.apa.org/style-grammar-guidelines/bias-free-language/age
  - https://cdn.who.int/media/docs/default-source/ageing/quick-guide-to-avoid-ageism-in-communication

- All manuscripts must meet the submission requirements set out in this document, closely following the instructions in the 'Preparation of manuscripts', 'Citation of references' and 'Table and Figures' sections below.

Preparation of manuscript (incl. references and tables)

All contributions (articles and book reviews) should be written in British English, and typed double-spaced with at least one-inch or two-centimetre margins throughout (including notes and the list of references). Please consult the section entitled 'Good written English', as well as the heading 'Submission of documents' before finalizing your submission.

For insight into the sections that most research articles include see the section on 'Article categories'. Below you will find detailed information that may be useful when preparing your manuscript.

The title page should give the title of the manuscript and the author(s)' names, affiliations and postal and email addresses. Please consult the headings 'Named authors' and 'ORCID' for further information.

When composing **the title of your manuscript**, please consider that the title will be shortened to appear as a running head in the final version of the Journal if your paper ends up being accepted for publication. Please note that allusions to specific countries and regions in the title can sometimes diminish the chances of an article being deemed relevant to readers who are based in other countries/ regions. Think therefore carefully about whether the title needs to include a specific geographical allusion. Note also that the use of quotes (i.e. data extracts) in a title can compromise how easily searchable an article is in certain databases.

Understanding the reasons why **abstracts** are included with a submission, and how they are used by reviewers/scholars, is crucial to crafting abstracts that do justice to the manuscript submitted whilst also providing an essential service to the scientific community**.** Thus, we would like to alert you to the fact that abstracts are the only information about a paper that reviewers receive when we request a review from them. Abstracts are also used when searching databases and making the decision to download and read a paper. It is for these reasons that abstracts are not meant to present a summary of the manuscript submitted, but rather to offer a service to members of the scientific community who are looking for contributions to ongoing debates. The abstract may contain a maximum of 300 words, and must contain the following information: an allusion to the knowledge gap, research problem or practice/ policy challenge that the study addresses, a statement about the study's aims, an allusion to the methods used (incl. sample size), a statement about the main results, as well as a statement about the contribution that the study makes to ongoing debates in social gerontology. In other words, a well-crafted abstract begins with a clear statement on the knowledge gap that the manuscript addresses and ends with a statement that spells out the type of contribution that the study makes to ongoing scholarly, practice and/or policy debates. The implications of the results for future research can be included in the final statement if applicable. Please note that abstracts should not include sub-headings, abbreviations that are undefined and references.

A well-crafted **introduction** conveys the reasons why a manuscript deserves the attention of the scientific community, and offers a hint to the type of contribution that a study makes. Thus, the **introduction** should not state matters that are obvious to this Journal's primary audience. General statements on population ageing, for example, make often little sense to our readers unless the manuscript argues something specific about the impact of population aging on the topic that the paper addresses. Thus, when constructing the introduction, aim to offer the scientific community the backdrop that makes the knowledge gap being addressed interesting and/or worthy of their attention.

Literature reviews are the sections that highlight the knowledge gap that a manuscript addresses. This section is not therefore meant to offer detailed information on a few studies, but to give the reader an idea of what characterises research on the topic that the manuscript addresses, and the kind of questions that remain unanswered. This means that the angles used to construct a literature review are multiple. Some literature reviews focus on the inconsistent results of previous research, while others argue that there are specific groups of older people that have not received attention. There are also literature reviews that argue that ongoing debates have been stifled by the fact that certain methodologies have been used less often, or because previous research has been conducted in certain parts of the world, to name but a few. Irrespective of which angle the literature review section of your manuscript will utilise, please keep in mind that it is the exposure of a knowledge gap that is the main objective of the literature review section of a research article.

Manuscripts that include a **theory** section should not only spell out what the theory proposes, they should also give readers an idea of which topics have been approached through the theoretical lens employed. Please note also that manuscripts that include a theory section should also engage with the theory presented in either the results sections or the discussion/ conclusion sections.

Manuscripts that report on empirical findings must detail the **research methodology** that the study has relied on. This means that information on research questions, hypotheses (when applicable), sampling strategies (incl. representativeness when applicable), sample characteristics and size, data collection and analysis as well as validity and reliability (or the equivalent for qualitative methodology) should be included in the methods section. Statements about ethical considerations are also expected in the section that focuses on methodology. The latter is particularly relevant when the data that a manuscript is based on was collected without having secured ethical approval from an ethics board. See also information under heading 'Ethical considerations'.

The **results/ findings** section of manuscripts submitted to this Journal can be constructed in several ways since we accept an array of methodological approaches, and these come with specific expectations as to how results/ findings should be presented. Manuscripts based on qualitative data, which sometimes rely on data extracts, should not end sections with a quote. In other words, the manuscript should interpret the data that it presents as opposed to leaving the analysis of data extracts to readers. Thus, the repetition of what the interview material utilized in the manuscript states should be avoided since this gives the impression that the analysis entails merely describing the data that has been collected, as opposed to analysing it and interpreting into a coherent message that can advance ongoing debates within social gerontology.

The **discussion/ conclusion** section should not only summarise the results presented (in the case of research articles) or the arguments conveyed (in the case of Forum articles). This section should spell out what the contributions of a paper are to ongoing debates in either research, policy and/or practice. In addition, the discussion should address the limitations that the methodological approach employed posed. Please note also that manuscripts need not include both a discussion and a conclusion section, which is why we write discussion/ conclusion. If the manuscript offers statements about the implications of the research presented for policy and practice, it is important to keep in mind the methodological limitations that sample size impose. Thus, authors are encouraged to remain cognizant that the robustness of the study design employed determines the cautiousness with which implications for policy or practice ought to be crafted.

Authors are asked to follow the **current style conventions** as closely as possible. Please consult a very recent issue of the journal. In particular, please note the following:

- Use the British variants of English-language spelling, so 'ageing', not 'aging'.
- **First level headers are in bold, sentence case and left justified**
- *Second level headers are in italic (not bold), sentence case and left justified*
- Do not number paragraphs or sections. Avoid very short (particularly one sentence) paragraphs.
- Do not use **bold text** in the text at all. For emphasis, use italic.
- ·In the main text, the numbers one to ten should be written as words, but for higher numbers the numerals (e.g. 11, 23, 364) should be used. However, if numbers are used in the very beginning of a sentence they should always be written as words.
- All acronyms must be expanded on first use, even EU (European Union), USA (United States of America), UK (United Kingdom) or UN (United Nations), to ensure that the article can be easily understood by all readers
- Do not use footnotes. Endnotes are permitted for technical and information details (including arrays of test statistics) that distract from the main argument. Endnote superscripts should be placed outside, not inside a punctuation mark (so.[3] not[4].).
- Write per cent (not %) except in illustrative brackets.

Good written English is a requirement for acceptance in *Ageing & Society*. We encourage authors to use all tools at their disposal to improve their writing such as Grammar and Spell Check in Microsoft Word, or additional tools such as Grammarly or Microsoft Editor. Authors, particularly those whose first language is not English, may wish to have their English-language manuscripts checked by a native speaker before submission. This is highly recommended since we need to ensure that the academic content of the paper is fully understood not only by the editor and the reviewers that will be consulted should we decide to send out your manuscript out to anonymous referees, but also by an international audience.

If you need additional support with your writing, we list a number of third-party services specialising in language editing and/or translation, and suggest that authors contact as appropriate:www.cambridge.org/core/services/authors/language-services

Please note that the use of any of these services is voluntary, and at the author's own expense. Use of these services does not guarantee that the manuscript will be accepted for publication, nor is the author required to submit to a Cambridge University Press journal after using the service.

Specific instructions regarding how **references** should be formatted both in text and in the reference list can be found under the heading 'Citation of references'.

Preparing your manuscript for peer review

- Because manuscripts that are deemed to meet the Journal's aims and scope are subjected to the anonymous peer-review process, the corresponding author should prepare (a) a complete text and (b) complete text minus the title page, acknowledgements, and any running headers of author names, to allow blinded review.

- References to papers of the authors must be blinded in both the text, and the list of references, until the review process has been completed.

- Authors may be asked to submit a revised version of the original manuscript after the first round of the peer-review process has taken place. In any revised submission, we prefer you to indicate these revisions by using either the track changes function, or a different font colour to indicate where revisions have been made. If substantial revisions have been made, the use of a different font colour is preferred.

- When submitting a revised version of a manuscript do include an enclosed letter (or a table) outlining how you have addressed the reviewers' comments, and stipulating which changes have been made. Comments on the advice that you have chosen not to accept should also be included in the accompanying letter/ table. The corresponding author should confirm that co-authors have agreed to any changes made.

Ethical considerations

- All papers must demonstrate that best practice and ethical standards have been met throughout the research design and execution, including adherence to the legal requirements of the author's institution.
- For empirical work conducted with human participants, authors must provide evidence that the study was subject to the appropriate level of ethical review. Authors must, in other words, state the full name of the body providing the favourable ethical review and reference number as appropriate. If full ethical approval was not required by your institution, please state this.
- Irrespective of whether the study was subjected to the appropriate level of ethical review or not, authors must still outline the ethical considerations that are appropriate for the study, and how they ensured that best practice was followed. This could form part of the ethical statement or, if more detailed explanation is required, be included in the methods section of the paper. For guidance on the issues to consider please see: www.ukri.org/councils/esrc/guidance-for-applicants/research-ethics-guidance
- If a manuscript relies on secondary data that does not require ethical approval, this too should be stated at the appropriate point in the submission process.

Declaration of funding

A declaration of sources of funding must be provided if appropriate. Authors must state the full official name of the funding body and grant numbers specified. Authors must also specify what role, if any, their financial sponsors played in the design, execution, analysis and interpretation of data, or writing of the study. If they played no role, this too should be stated.

Conflicts of interest declaration

All authors must include a conflicts of interest declaration in their title page. This declaration will be subject to editorial review and will be published in the article. Conflicts of interests are situations that could be perceived to exert an undue influence on the content or publication of an author's work. They may include, but are not limited to, financial, professional, contractual or personal relationships or situations. If the manuscript has multiple authors, the author submitting must include conflicts of interest declarations relevant to all contributing authors. Example wording for a declaration is as follows: "Conflicts of interest: Author A is employed at company B. Author C owns shares in company D, is on the Board of company E and is a member of organisation F. Author G has received grants from company H." If no conflicts of interest exist, the declaration should state "Conflicts of interest: The author(s) declare none".

Citation of references

Ageing & Society uses an author-date system in which sources are cited parenthetically in text and full publication details appear in the reference list. The journal style seeks to use the minimum punctuation necessary.

In-text citation

Give the author's surname, date of publication and page references (if any) in parentheses in the body of the text, e.g. (Cole 1992) or (Cole 1992, 251). For references with two authors, both authors should be named (Green and Brown 2003). For references with three or more authors, the following form is required: (Brown et al 2003).

To cite several authors in one place, and/or several references by the same author use:

(Ferraro 2018; Keating 2012, 2019; Schatz 2021)

Reference list

A complete list of references cited, arranged alphabetically by authors' surname, should be typed double-spaced at the end of the article. Note that all authors must be named in the list of references, and et al is not permitted in the list. List two or more works by the same author or authors chronologically. To distinguish two or more works by the same author or authors in the same year, use a, b, c, etc. following the date, and list references in the order in which they are mentioned in the text.

Note also that while the manuscript is undergoing the review process, references to authors' work should remain anonymous. Thus, when such references are included in the original submission, list them as AUTHOR 1, 2010, AUTHOR 3, 2018 etc. Once a manuscript has been accepted for publication, we will request that these anonymized references be added.

The reference list should follow this form:

For books

Cole T (1992) *The Journey of Life: A Cultural History of Aging in America.* Cambridge: Cambridge University Press

Ruth J-E and Oberg P (1996) Ways of life: old age in life history perspective. In Birren JE, Kenyon G, Ruth J-E, Schroots J F F and Svensson T (eds), *Aging and Biography: Explorations in Adult Development.* New York: Springer, 167-86.

For journal articles

It is not necessary to provide an issue number of journals paginated by volume:

Smith K & Victor C (2019) Typologies of loneliness, living alone and social isolation, and their associations with physical and mental health. *Ageing & Society* **39**, 1709-1730. https://doi.org/10.1017/S0144686X18000132

Elder G H and Clipp E C (1988) Wartime losses and social bonding: influences across 40 years in men's lives. *Psychiatry: Interpersonal and Biological Processes* **51**(2), 177-98. https://doi.org/10.1080/00332747.1988.11024391

For online interviews or articles

Thompson D (2020) How long does COVID-19 immunity last? *Atlantic*, 20 July. Available at https://www.theatlantic.com/ideas/archive/2020/07/could-covid-19-immunity-really-disappearmonths/614377/ (accessed 20 July 2020).

Aung San Suu Kyi (2017) Interview by F Keane, 5 April 2017. BBC News. Available at https://www.bbc.com/news/av/worldasia-39510271/myanmar-aung-san-suu-kyi-exclusive-interview (accessed 20 July 2020).

For the reference list, please particularly note the following:

- *Titles of Books and Journals are in Title Case and Italic.*
- Titles of papers, articles and book chapters are in sentence case and not italicised.
- Do not elide page numbers when giving page ranges (thus, it should be 213-229 rather than 213-29).
- Authors are requested to minimise the citation of unpublished working and conference papers (because they are difficult for readers to acquire). Where they are cited, complete details of the title of the conference, the convening organisation, the location and the date of the presentation must be given.
- Papers that have been submitted to a journal but on which no decision has been heard must not be cited.

For full details of the *Ageing & Society* reference style, and more examples, please see Cambridge A in the reference style guide.

Tables and figures

There should never be more than ten tables and figures in aggregate, and only in exceptional circumstances more than eight. Please do not use Boxes or Appendices. Present all illustrative material as tables or figures. Please indicate in the text where approximately the Table and Figures should appear using the device < Insert Table 1 about here > on its own line.

Tables should be clearly laid out on separate pages, numbered consecutively, and designed to fit into a space of 184 x 114mm. Tables should have titles describing their content above the body of the table in sentence case.

Vertical lines between columns should be omitted and horizontal lines should be used only at the top and bottom of the table and below column headings. Totals and percentages should be labelled, and units identified. Authors are asked to give particular attention to the title and to column and row labels so that tables are comprehensible without reference to the text. Authors should avoid using figures with an excessive number of digits and rescale variables so that all figures in a table can be displayed with the same number of digits after decimal points, ideally nor more than 3. Use initial zeros, i.e., 0.300 rather than .300.

Technical or methodological details (such as sample size or type of statistic) should be described in the labels or in table notes. Within tables, references to notes should be indicated with superscript numerals. The explanations should be given in 'Notes:' under the body of the table, using a continuous paragraph.

'*Significance levels:*' and '*Sources:*', where required, should be in paragraphs separate from the general notes, and have italicised opening headers.

Example table:

TABLE 1. *Unstandardised regression coefficients predicating the life satisfaction of older people in rural areas, Republic of China, 2003*

Variable or measure	Model 1		Model 2	
	β	SE	β	SE
Depression at Wave 1	0.27***	0.03	0.27***	0.03
Socio-demographic variables at Wave 1:				
Age	0.01	0.01	0.01	0.01
Female	−0.08	0.14	−0.09	0.14
Married	−0.32	0.18	−0.32	0.18
Education	−0.18	0.15	−0.19	0.15
Total number of children	0.09*	0.04	0.12**	0.04
Living with offspring at Wave 1[1]	0.44*	0.18	0.45*	0.18
Total number of migrant children at Wave 1			−0.09†	0.06
R^2	0.25		0.26	
Sample size	1,237		1,237	

Notes: 1. Reference category is living alone. SE: standard error. β: standardised regression coefficient.
Significance levels: † $p < 0.1$, * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

Figures should also be provided on separate pages, numbered consecutively and designed to fit a printed page of 228 x 152 mm (actual text area 184 x 114 mm). For each figure, the caption should be below and in sentence case. Separate lists of captions are not required. For figures generated by Excel, please send the original file (rather than an exported image) so that the figures can be copy-edited.

Figures should be provided in the following formats:

- **TIFF (.tif)** is the recommended file format for line art, greyscale and colour halftone images. TIFF files should be compressed once created, ensuring file sizes are kept to a minimum to aid easy file transfer. When saving as TIFF format, please ensure that LZW compression is applied. **Recommended for: all images**

- **EPS (.eps)** For vector graphics, EPS files are the preferred format. An EPS file is an image that has been created using the language of PostScript, and is generally resolution independent. **Recommended for: line and combination artwork**

- **PDF (.pdf)** This format is very similar to EPS. Before saving an image as a PDF it is important to make sure that the fonts are embedded and that the original images are at the correct size and resolution. To check this visually you can zoom in when viewing the PDF on screen.

For further information about how to prepare your figures, including sizing and resolution requirements, please see our artwork guide.

Colour figures can be submitted to *Ageing & Society*, but charges apply for all colour figures that appear in the print version of the journal. At the time of submission, contributors should clearly state whether their figures should appear in colour in the online version only, or whether they should appear in colour online *and* in the print version. There is no charge for including colour figures in the online version but you should ensure that any colour figures are still legible when produced in grayscale for the printed version. If you request colour figures in the printed version, you will be contacted by CCC-Rightslink who are acting on our behalf to collect Author Charges. Please follow their instructions in order to avoid any delay in the publication of your article.

Supplementary materials

Authors are encouraged to publish supplementary material online wherever it serves to enhance the argument or otherwise enrich an article. This could include, but will not necessarily be limited to anonymised data, slides, large images, videos, and audio files. A full set of file specifications and instructions concerning supplementary material of this kind can be found here.

Each supplementary file must be supplied as a separate file. Do not supply this material as part of the main body of the article. All supplementary material should be submitted with the original manuscript submission so that they can be considered as part of the peer review process.

Please note that if the article is accepted, Supplementary materials are not edited or typeset, and are published online with the full article in exactly the format supplied by the authors.

Preparing your documents for submission

All submissions should include:

- A copy of the complete text of the manuscript, with a title page including the title of the article and the author(s)' names, affiliations and postal and email addresses, and conflicts of interest declaration (see below for guidance on what this should look like).

- A copy of the complete text minus the title page, acknowledgements, any running headers of author names and blinded references to authors' previous work, to allow for anonymous peer-review.

Named authors

- Papers with more than one author must designate a corresponding author. The corresponding author should be the person with full responsibility for the work and/or the conduct of the study, had access to the data, and controlled the decision to publish. The corresponding author must confirm that co-authors have read the paper and are aware of its submission. Full contact details for all co-authors should be submitted via Manuscript Central.

- You must ensure that you have included all authors and provided their correct information before submission. We may not be able to accommodate changes to the author list after the manuscript has been accepted.

- All named authors for an article must have made a substantial contribution to: (a) the conception and design, or analysis and interpretation of data; (b) the drafting of the article or revising it critically for important intellectual content and (c) approval of the version to be published. All these conditions must all be met. Participation solely in the acquisition of funding or the collection of data does not, of itself, justify authorship. On submission, the Corresponding Author must declare that they have the authority of all co-authors for the submission.

Author affiliations

Author affiliations should represent the institution(s) at which the research presented was conducted and/or supported and/or approved. For non-research content, any affiliations should represent the institution(s) with which each author is currently affiliated.

For more information, please see our author affiliation policy and author affiliation FAQs.

ORCID

Ageing & Society now requires that all corresponding authors identify themselves using ORCID when submitting a manuscript to the journal. ORCID provides a unique identifier for researchers and, through integration in key research workflows such as publication and grant applications, provides the following benefits:

1. Discoverability: ORCID increases the discoverability of your publications, by enabling smarter publisher systems and by helping readers to reliably find work that you've authored.

2. Convenience: As more organisations use ORCID, providing your ID or using it to register for services will automatically link activities to your ORCID profile (if you give permission), and will save you re-keying information multiple times.

3. Keeping track: Your ORCID profile is a neat place to record and display (if you choose) validated information about your research activities.

If you do not already have an ORCID ID, you will need to create one if you decide to submit a manuscript to *Ageing & Society*. You can register for one directly from your account on ScholarOne or via https://ORCID.org/register If you already have an ID, please use this when submitting by linking it to your ScholarOne user account. Simply log in to your account using your normal username and password. Edit your account by clicking on your name at the top right of the screen and from the dropdown menu, select 'E-Mail / Name'. Follow the instructions at the top of the screen to update your account. For more information about why we are making this change please see https://www.cambridge.org/core/services/authors/journals/using-orcid.

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If your article contains any material in which you do not own copyright, including figures, charts, tables, photographs or excerpts of text, you must obtain permission from the copyright holder to reuse that material. As the author it is your responsibility to obtain this permission and pay any related fees, and you will need to send us a copy of each permission statement at acceptance. For more information, please see our guidance on copyrighted material.

Appendix O: TDRP - Email Advertisement - Experts Focus Group

RE: Research – Invitation to attend a focus group consulting on the development of a new adolescent sensory coping measure

Dear colleague,

I hope this email finds you well. My colleagues, Dr Carmen Chan, Dr James Stacey, Dr Myra Cooper, and I are currently undertaking research developing a sensory modulation measure for adolescents. This research has derived from the ongoing difficulty distinguishing between ASD and interpersonal trauma due to their many similar features. Within this research study we wanted to focus specifically on sensory modulation across different clinical groups, however quickly realised that although there are existing measures around sensory sensitivities, there isn't any that comprehensively explore management strategies.

Our research therefore is centred around developing a questionnaire which we hope will measure how young people manage sensory experiences within the general population as well as within different clinical groups.

Questionnaire items will be developed through a focus group with young people experiencing sensory sensitivity. We would like to hold another focus group of professionals to finalise the questionnaire.

We are looking for professionals who work with young people who experience sensory sensitivities, particularly those who may have an ASD diagnosis and/or a history of interpersonal trauma, to attend a focus group to review questionnaire items and to consult on the finalisation of the measure.

Please follow this link for more information about the study and to provide your consent should you wish to take part https://bit.ly/3qfoZlO.

If you have any questions or concerns, please feel free to contact me [email address]. I will try wherever possible to arrange the focus group for a time that is most convenient for you.

I would also be grateful if you wouldn't mind sharing this email with anyone you think may be interested.

Many thanks.

Best wishes,
[Trainee]

Appendix P: TDRP - Information Sheet - Focus Group

Chief Investigator:
Eloise Maguire, Trainee Clinical Psychologist
Oxford Institute of Clinical Psychology Training and Research
eloise.ainger@hmc.ox.ac.uk

The Development of an Adolescent Sensory Coping Measure for use within Non-Clinical and Clinical Presentations

EXPERTS IN THE FIELD FOCUS GROUP PARTICIPANT INFORMATION SHEET

1. Why is this research being conducted?

Research suggests that sensory processing exists on a continuum in the general population, and that key difficulties in processing and modulation exist within multiple clinical groups. It is well established within clinical practice that autistic individuals and those who have experienced interpersonal trauma share a number of key features, which can lead to misdiagnosis and difficulties being missed. It is possible however, that these two groups may differ in the way they modulate their sensory experiences.

There are currently no appropriate measures that enable an exploration of sensory modulation. This study therefore aims to develop a measure to identify management strategies used by the general population to modulate sensory experiences, and to further validate its use by applying it to groups of autistic young people and those who have experienced interpersonal trauma.

Questionnaire items will be developed through literature searching, a focus group with service users experiencing sensory sensitivities, and a focus group with experts in the field. The questionnaire will then be rolled out to the general population of 13–18-year-olds. Following the finalisation of the questionnaire, young autistic individuals and individuals who have experienced interpersonal trauma will complete the final measure to explore any differences.

You are being invited to take part in the experts focus group.

2. Why have I been invited to take part?

You have been invited because you are a professional working in the field of child and adolescent mental health services, intellectual disabilities and/or neurodevelopmental disorders, including ASD and interpersonal trauma with experience of working with young people who have sensory processing and/or modulation difficulties.

3. Do I have to take part?

No. You can ask questions about the research before deciding whether or not to take part. If you do agree to take part, you may withdraw yourself from the study, without giving a reason, by advising us of this decision.

4. What will happen to me if I take part in the research?

You will be asked to attend one focus group session which will take place online. This will be facilitated by the researcher, and consist of 6-8 professionals participating in the discussion. The focus group will focus on reviewing collated questionnaire items gathered from a literature search and focus groups with young people. You will be asked to comment on the items and add or amend any based on your professional experience.

At the beginning of the focus group, I will talk you through the procedure and give you the chance to ask any questions. If you are still happy to take part, I will ask you to sign a consent form.

If you are happy to take part in the research, the focus group will take place via MS Teams at a time that is convenient to you. The focus group should take approximately 40-60 minutes. Please ensure you are in a safe, quiet space before joining the focus group to ensure confidentiality. You can also ask to pause or stop the focus group at any time should you feel compromised or uncomfortable.

With your consent, we would like to audio record you so we can have an accurate record of your thoughts.

5. Are there any potential risks in taking part?

There is a potential risk of breaking confidentiality if you discuss certain young people you are working with. To reduce any potential risks, participants will be asked to use anonymised examples and not to share what was discussed outside of the group. Your personal data will be pseudonymised as appropriate.

If you become distressed or want to discuss anything outside of the group setting, please feel free to contact Eloise Maguire on eloise.ainger@hmc.ox.ac.uk.

Alternatively, please find further wellbeing support and contact details via the staff intranet: http://www.oxfordhealth.nhs.uk/youmatter/

6. Are there any benefits in taking part?

There will be no direct or personal benefit to you from taking part in this research, however we hope this measure will be clinical applicable in a range of different presentations, allowing exploration of differences across groups. We hope this measure will act as a helpful first step to distinguishing between those who have experienced interpersonal trauma and autistic individuals.

7. How will we use information about you?

We will need to use information from you for this research project.

This information will include your:

- Name
- Contact details
- Age range
- Gender
- Ethnicity
- Job role
- Service type
- Number of years experience working with individuals with sensory sensitivities

We will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

Personal data and audio recordings will be stored electronically on an encrypted password protected NHS computer and secure server One Drive. Data will only be accessible to the researcher and supervisors. Personal data will be kept for three years and then will be destroyed. Audio recordings will be transcribed by the researcher and then deleted. The transcription will be kept for 10 years and then destroyed.

Other research data (including consent forms) will be stored for at least 3 years after publication or public release of the work of the research, in line with University policy. The researcher and supervisors will have access to the research data. Responsible members of the University of Oxford may be given access to data for monitoring and/or audit of the research. We would like your permission to use direct quotes against a pseudonym in any research outputs.

8. Where can you find out more about how your information is used?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- our leaflet available from https://www.oxfordhealth.nhs.uk/privacy/
- by asking or contacting one of the research team [eloise.ainger@hmc.ox.ac.uk]
- by sending an email to Oxford Health Data Protection Officer at mark.underwood@oxfordhealth.nhs.uk

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO) (www.ico.org or 0303 123 1113).

9. What will happen if I don't want to carry on with the study?

You can stop being part of the study at any time, without giving a reason, but we may not be able to withdraw the information about you that we already have. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

10. Will the research be published?

The research may be published in academic publications.

The University of Oxford is committed to the dissemination of its research for the benefit of society and the economy and, in support of this commitment, has established an online archive of research materials. This archive includes digital copies of student theses successfully submitted as part of a

University of Oxford postgraduate degree programme. Holding the archive online gives easy access for researchers to the full text of freely available theses, thereby increasing the likely impact and use of that research.

The research will be written up as a student's thesis. On successful submission of the thesis, it will be deposited both in print and online in the University archives to facilitate its use in future research. If so, the thesis will be openly accessible.

11. What if something goes wrong?

If you have any concerns about the way you have been approached or treated during the study, please talk to, Eloise Maguire, Chief Investigator, Oxford Institute of Clinical Psychology Training and Research, Isis Education Centre, Warneford Hospital, Oxford, tel: 01865 226431, email: eloise.ainger@hmc.ox.ac.uk or Dr Myra Cooper: 01865 226431, myra.cooper@ox.ac.uk

If you wish to speak to an independent body about any concerns or complaints about any aspect of the way you have been approached or treated during this study, you can do this by raising it directly within your organisation, or alternatively by contacting enquiries@improvement.nhs.uk to raise your concerns.

12. Who has reviewed this study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect participants' interests. This study has been reviewed and given favourable opinion by Hertfordshire and Cambridgeshire Research Ethics Committee (22/EE/0031). This study has been also reviewed by, and received ethics clearance through, Oxford Health Foundation Trust.

13. Further Information and Contact Details

If you would like to discuss the research with someone beforehand (or if you have questions afterwards), please contact:
Eloise Maguire, Oxford Institute of Clinical Psychology Training and Research, Isis Education Centre, Warneford Hospital, Oxford.
Tel: 01865 226431, email: eloise.ainger@hmc.ox.ac.uk

Appendix Q: TDRP - Consent Form – Experts in the Field Focus Group

Chief Investigator:
Eloise Maguire, Trainee Clinical Psychologist
Oxford Institute of Clinical Psychology Training and Research
eloise.ainger@hmc.ox.ac.uk

EXPERT FOCUS GROUP PARTICIPANT CONSENT FORM

IRAS Reference: [22/EE/0031]

The Development of an Adolescent Sensory Coping Measure for use within Non-Clinical and Clinical Presentations

		Please tick each box
1	I confirm that I have read and understand the information sheet version 2 dated 18/02/2022 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
2	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without any adverse consequences or penalty.	☐
3	I understand that research data collected during the study may be looked at by authorised people outside the research team. I give permission for these individuals to access my data.	☐
4	I understand who will have access to personal data provided (including name and email address), how the data will be stored and what will happen to the data at the end of the project.	☐
5	I agree to audio recording and the general themes of our discussions to be included in research reports and publications. No individual quotes will be published.	☐
6	I agree to take part in the study	☐

Name _____ Date_____
Email address (We will use this to send to send you a link to the focus group): _____

Researcher signature: _____ Date:

A signed copy of this consent form will be sent to you via email. The research team will also keep a copy of this form.

Appendix R: TDRP - Information Sheet – Young People Consultation CAMHS Sample (13-15yrs)

Chief Investigator:
Eloise Maguire, Trainee Clinical Psychologist
Oxford Institute of Clinical Psychology Training and Research
eloise.ainger@hmc.ox.ac.uk

The Development of an Adolescent Sensory Coping Measure for use within Non-Clinical and Clinical Presentations

SERVICE USER FOCUS GROUP/ONLINE SURVEY (13-15yrs) PARTICIPANT INFORMATION SHEET

We would like you to help us with our research study. Please read this information carefully and talk to your mum, dad or carer about the study. They also have some information to read. If you don't want to take part, that's fine, your care at CAMHS will be the same. If you would like to take part, your parent will also need to sign a consent form.

1. Why are we doing this research?

We all experience "sensory input" all the time. Sensory input is when our senses are being used, such as sight, hearing, smell, taste, and touch. It can also be movement and the sense of our bodies. We all experience these things differently. For some people, sensory input (like noise and smells) are more difficult to process and manage. This can mean they might experience certain things more or less intensely than others. This can be uncomfortable for some.

At the moment, we don't have a good way of measuring how people manage sensory input. We are developing a questionnaire that will help us understand how people manage sensory experiences. First, we would like to speak to young people experiencing sensory sensitivity. This will help us decide on the questions for the questionnaire. We will then talk to a group of experts. Once the questionnaire is complete, we will ask young people to complete it. We will then finalise the questionnaire and ask autistic individuals and individuals who have

experienced difficult life experiences to complete the questionnaire. This will tell us if there are any differences in the way they manage sensory input.

You are being invited to take part in talking to us about your sensory experiences. You will have the option to take part in an interview or focus group, or to complete an online survey.

2. Why have I been invited to take part?

You have been invited because you are between the ages of 13-18 years and receive support from a Child and Adolescent Mental Health Team (CAMHS). You may have some experience of finding sensory input difficult and may use different methods to help.

3. Do I have to take part?

No. You can ask questions about the research before deciding whether or not to take part. If you do agree to take part, you can stop at any time by telling us. You do not have to tell us why.

4. What will happen to me if I take part in the research?

You may choose how you would like to take part, either through attending a focus group, interview, or completing an online survey.

Focus groups/interviews: You will be asked to attend 1 focus group/interview session which will take place online. A focus group is a group of people discussing a topic together. Around 6-8 young people will be there to join in the discussion. If you choose to attend an interview, you will meet with one researcher only. A researcher will ask questions.

The focus group/interview/survey will take place online. What you share is private. If joining a focus group or interview, you should be in a safe, quiet space. The focus group will take around 40-60 minutes. You can also ask to pause or stop the focus group at any time. You may choose to do this if you feel uncomfortable, or you are no longer in a safe space. With your consent, we would like to audio record you so we can have an accurate record of your thoughts.

Online Survey: If you would prefer to complete an online survey you will be sent a link to do so. The survey should take approximately 10-15 minutes. At the end of the survey we will ask if you would like to also talk to us by telephone. This is optional.

We will ask you about your experiences of sensory input. We will ask about any sensory inputs you like or don't like, and what you do when you experience them. We will also ask you about what you think should be in the questionnaire.

If you are happy to take part, I will ask you to complete an assent form. A parent or carer will also need to read their information sheet and complete a parent consent form to say they agree for you to take part. You will have a chance to ask any questions before the focus group begins.

5. Is there anything to worry about if I take part?

If you decide to take part in the focus group we will ask you to share your experiences with the group. It is possible that others in the group may share what you say with other people. We will ask everyone in the group to not do this. This will make sure what you share will be kept private. The information you give us will be given a code. We won't use your name in the written reports to reduce the chance of you being recognised.

If you become upset or want to discuss anything outside of the group setting, you or your parents/carer can contact Eloise Maguire on eloise.ainger@hmc.ox.ac.uk.

Alternatively, if you feel you need to speak with someone for support, please see below for details of how to do so:

- Call 111 for the 24/7 Mental Health Helpline
- Call Samaritans (116 123) any time of day for free confidential support

You may find further information and helpful tools on the following websites:

- Oxford Health CAMHS website: https://www.oxfordhealth.nhs.uk/camhs/self-care/
- YoungMinds website: https://www.youngminds.org.uk

It can be helpful to discuss how you are feeling with someone you know and trust. This may be a parent, teacher, school nurse, friend, family member, GP or other professional.

6. Are there any benefits in taking part?

This study will not directly help you but the information you provide will help us create a questionnaire. We hope this can be used by professionals to help understand how different people manage their sensory experiences. This will enable them to know how to help. You will also be provided with a voucher.

7. How will we use information about you?

We will need to use information from you for this research project.

This information will include your:

- Name
- Contact details

- Age range
- Gender
- Ethnicity
- Any diagnoses related to sensory sensitivities

We will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

We will keep a document that links your code and your information. This document will be kept secure and private. Only the researcher will access this. After we type up what was said in the focus group, the recording will be deleted. Data will only be seen by the researcher and supervisors. This information will be kept for three years and then will be destroyed.

Other research data (including consent forms) will be kept for 10 years after publication. Only the researcher and supervisors will have access to the research data. It may also be shared with a sponsor's representative.

8. Where can you find out more about how your information is used?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- our leaflet available from https://www.oxfordhealth.nhs.uk/privacy/
- by asking or contacting one of the research team [eloise.ainger@hmc.ox.ac.uk]

- by sending an email to Oxford Health Data Protection Officer at mark.underwood@oxfordhealth.nhs.uk

If you want to make a complaint about how we handled your personal information, you or your parents/carers can contact our Data Protection Officer. If you are not happy with our response you can complain to the Information Commissioner's Office (ICO) (www.ico.org or 0303 123 1113).

9. What will happen if I don't want to carry on with the study?

You can stop being part of the study at any time. You do not have to tell us why. We may not be able to withdraw the information about you that we already have. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

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

This study will be part of the researchers Clinical Psychology training. The results will be written up in a report and given to teachers and other students at the University. The report might also be published in a scientific magazine. You will not be personally identified in the reports. This means that you can't be recognised in the reports.

11. What if something goes wrong?

If you or your parents/carers have any worries about the way you were treated during the study, please talk to Eloise Maguire, Chief Investigator, Oxford Institute of Clinical Psychology Training and Research, Isis Education Centre, Warneford Hospital, Oxford, tel: 01865 226431, email: eloise.ainger@hmc.ox.ac.uk or Dr Myra Cooper: 01865 226431, myra.cooper@ox.ac.uk

If you would like to speak to someone outside of the study about any concerns or complaints, you can do this through the Patient Advice and Liaison Service (PALS). PALS, Oxford Health NHS Foundation Trust, PALS Office, Warneford Hospital, Warneford Lane, Oxford OX3 7JX. Tel: 0800 3287971. E-mail: PALS@oxfordhealth.nhs.uk

12. Who has reviewed this study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect participants' interests. This study has been reviewed and given favourable opinion by Hertfordshire and Cambridgeshire Research Ethics Committee

(22/EE/0031). This study has been also reviewed by, and received ethics clearance through, Oxford Health Foundation Trust.

13. Further Information and Contact Details

If you would like to discuss the research with someone beforehand (or if you have questions afterwards), please contact:

Eloise Maguire, Oxford Institute of Clinical Psychology Training and Research, Isis Education Centre, Warneford Hospital, Oxford.

University tel: 01865 226431, University email: eloise.ainger@hmc.ox.ac.uk

Appendix S: TDRP - Information Sheet – Young People Consultation CAMHS Sample (16-18yrs)

Chief Investigator:
Eloise Maguire, Trainee Clinical Psychologist
Oxford Institute of Clinical Psychology Training and Research
eloise.ainger@hmc.ox.ac.uk

The Development of an Adolescent Sensory Coping Measure for use within Non-Clinical and Clinical Presentations

SERVICE USER FOCUS GROUP/ONLINE SURVEY (16-18yrs)
PARTICIPANT INFORMATION SHEET

1. Why is this research being conducted?

We all experience "sensory input" all the time. Sensory input is when our senses are being used, such as when we are looking at something, hearing a noise, smelling something, taste, and touch. It can also be movement and the sense of our bodies. We all experience these things differently. For some people, sensory input (like noise and smells) are more difficult to process and manage. For example, for some autistic individuals and some people who have had difficult things happen in their life. These individuals also share a lot of other common features. This can make it harder for professionals to diagnose correctly and help them in the most appropriate way. We think that the way they manage sensory input might be one way they differ.

At the moment, we don't have a good way of measuring how people manage sensory input as there are no questionnaires that look at this. This study therefore aims to develop a questionnaire that will help us understand how people generally manage sensory input or experiences. First, we would like to speak to young people experiencing sensory sensitivity. This will help us develop the questions for the questionnaire. We will then also ask a group of experts. Once the questionnaire is complete, we will ask young people to complete it. We will then finalise the questionnaire and ask autistic individuals and individuals who have

experienced difficult life experiences to complete the questionnaire. This will tell us if there are any differences in the way they manage sensory input.

You are being invited to take part in talking to us about your sensory experiences. You will have the option to take part in an interview or focus group, or to complete an online survey.

2. Why have I been invited to take part?

You have been invited because you are between the ages of 13-18 years and receive support from a Child and Adolescent Mental Health Team (CAMHS). You may have some experience of finding sensory input difficult and may use different methods to help.

3. Do I have to take part?

No. You can ask questions about the research before deciding whether or not to take part. If you do agree to take part, you can stop at any time by telling us. You do not have to tell us why.

4. What will happen to me if I take part in the research?

You may choose how you would like to take part, either through attending a focus group, interview, or completing an online survey.

Focus groups/interviews: You will be asked to attend 1 focus group/interview session which will take place online. This will be led by the researcher and include 6-8 young people joining in the discussion. The conversation will be focused on your experiences of sensory input. If you choose to attend an interview, you will meet with one researcher only.

The focus group/interview will take place via MS Teams at a time that is convenient to you. The focus group is confidential. You should take care to ensure you are in a safe, quiet space before joining the focus group. The focus group should take approximately 40-60 minutes. You can also ask to pause or stop the focus group at any time. You may choose to do this if you feel uncomfortable, or you are no longer in a safe space, away from others. With your consent, we would like to audio record you so we can have an accurate record of your thoughts.

Online Survey: If you would prefer to complete an online survey you will be sent a link to do so. The survey should take approximately 10-15 minutes. At the end of the survey we will ask if you would like to also talk to us by telephone. This is optional.

During the interview/focus group/survey, we will ask about any discomfort or preferences for particular sensory inputs, and the ways you cope with these experiences. We will also ask you about what you think would be important to include in the questionnaire.

You will have an opportunity to ask any questions about the study and will then be asked to sign a consent form. Once received, you will either be sent a link to the online survey, or to the focus group/interview.

5. Are there any potential risks in taking part?

If you decide to take part in the focus group we are asking you to share your experiences with the group. It is possible that confidentiality may be broken. We will ask everyone to not share what they have heard in the group with other people. This will make sure what you share will be kept private. Your information and what you say will be pseudonymised. This means your name will be changed in the written records to reduce the chance of you being identified.

If you become upset or want to discuss anything outside of the group setting, please feel free to contact Eloise Maguire on eloise.ainger@hmc.ox.ac.uk.

Alternatively, if you feel you need to speak with someone for support, please see below for details of how to do so:

- Call 111 for the 24/7 Mental Health Helpline
- Call Samaritans (116 123) any time of day for free confidential support

You may find further information and helpful tools on the following websites:

- Oxford Health CAMHS website: https://www.oxfordhealth.nhs.uk/camhs/self-care/
- YoungMinds website: https://www.youngminds.org.uk

It can be helpful to discuss how you are feeling with someone you know and trust. This may be a parent, teacher, school nurse, friend, family member, GP or other professional.

6. Are there any benefits in taking part?

There will be no direct or personal benefit to you from taking part in this research. We hope that this study however will lead to a measure that can be used by different professionals to help us understand how different people manage their sensory experiences. You will be provided with a monetary voucher.

7. How will we use information about you?

We will need to use information from you for this research project.

This information will include your:

- Name
- Contact details
- Age range
- Gender
- Ethnicity
- Any diagnoses related to sensory sensitivities

We will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

A document linking your code to your data will be kept in a password protected document and only the researcher will be able to access this. All data, including audio recordings and transcriptions will be stored electronically on an encrypted password protected NHS computer and a secure service One Drive. Recordings will be destroyed after being transcribed by the researcher. Data will only be seen by the researcher and supervisors. This information will be kept for three years and then will be destroyed.

Other research data (including consent forms) will be stored for 10 years after publication or public release of the work of the research. The researcher and supervisors will have access to the research data. Responsible members of the sponsor's representative may be given access

to data for monitoring and/or audit of the research. We would like your permission to use direct quotes against a made-up name in any research outputs.

8. Where can you find out more about how your information is used?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- our leaflet available from https://www.oxfordhealth.nhs.uk/privacy/
- by asking or contacting one of the research team [eloise.ainger@hmc.ox.ac.uk]
- by sending an email to Oxford Health Data Protection Officer at mark.underwood@oxfordhealth.nhs.uk

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO) (www.ico.org or 0303 123 1113).

9. What will happen if I don't want to carry on with the study?

You can stop being part of the study at any time, without giving a reason, but we may not be able to withdraw the information about you that we already have. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

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

This study will be part of the researchers Clinical Psychology training. The results will be written up in a report and given to teachers and other students at the University. The report might also be published in a scientific magazine. You will not be personally identified in the reports.

11. What if something goes wrong?

If you have any concerns about the way you have been approached or treated during the study, please talk to, Eloise Maguire, Chief Investigator, Oxford Institute of Clinical Psychology Training and Research, Isis Education Centre, Warneford Hospital, Oxford, tel: 01865 226431, email: eloise.ainger@hmc.ox.ac.uk or Dr Myra Cooper: 01865 226431, myra.cooper@ox.ac.uk

If you wish to speak to an independent body about any concerns or complaints about any aspect of the way you have been approached or treated during this study, you can do this through the Patient Advice and Liaison Service (PALS). PALS, Oxford Health NHS Foundation Trust, PALS Office, Warneford Hospital, Warneford Lane, Oxford OX3 7JX. Tel: 0800 3287971. E-mail: PALS@oxfordhealth.nhs.uk

12. Who has reviewed this study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect participants' interests. This study has been reviewed and given favourable opinion by Hertfordshire and Cambridgeshire Research Ethics Committee (22/EE/0031). This study has been also reviewed by, and received ethics clearance through, Oxford Health Foundation Trust.

13. Further Information and Contact Details

If you would like to discuss the research with someone beforehand (or if you have questions afterwards), please contact:

Eloise Maguire, Oxford Institute of Clinical Psychology Training and Research, Isis Education Centre, Warneford Hospital, Oxford.

University tel: 01865 226431, University email: eloise.ainger@hmc.ox.ac.uk

Appendix T: TDRP - Information Sheet – Young People Consultation CAMHS Sample (parent)

Chief Investigator:
Eloise Maguire, Trainee Clinical Psychologist
Oxford Institute of Clinical Psychology Training and Research
eloise.ainger@hmc.ox.ac.uk

The Development of an Adolescent Sensory Coping Measure for use within Non-Clinical and Clinical Presentations

SERVICE USER FOCUS GROUP/ONLINE SURVEY
PARENT INFORMATION SHEET

1. Why is this research being conducted?

We all experience "sensory input" (e.g. sight, sounds, smells, tastes, touch, movement) differently. For some people, such as autistic individuals or those who have experienced trauma, sensory input is more difficult to process and manage. These individuals also share a lot of other key features which can lead to misdiagnosis and difficulties being missed. It is possible however, that these two groups may differ in the way they manage their sensory experiences.

At the moment, we don't have a good way of measuring how people manage sensory input. This study therefore aims to develop a questionnaire that will help us understand how people generally manage sensory input or experiences.

Questionnaire items will be developed through literature searching, speaking with service users experiencing sensory sensitivities, and a focus group with experts in the field. The questionnaire will then be rolled out to the general population of 13–18-year-olds. Following the finalisation of the questionnaire, young autistic individuals and individuals who have experienced interpersonal trauma will complete the final measure to explore any differences.

Your child is being invited to take part talking to use about their sensory experiences. They will have the option to take part in an interview or focus group, or to complete an online survey.

We will then ask autistic individuals and individuals who have experienced difficult life experiences to complete the questionnaire, which will tell us if there are any differences in the way they manage sensory input.

2. Why has my child been invited to take part?

Your child has been invited to take part because they are between the ages of 13-18 years and receive support from a Child and Adolescent Mental Health Team (CAMHS). They may also have some experience of finding sensory input difficult and may use different methods to help.

3. Do they have to take part?

No. You and your child can ask questions about the research before deciding whether or not to take part. If you do agree to take part, they can stop at any time by telling us and without giving a reason.

4. What will happen to my child if they take part in the research?

Your child may choose how they would like to take part, either through attending a focus group, interview, or completing an online survey.

Focus groups/interviews: Your child will be asked to attend 1 focus group/interview session which will take place online. This will be led by the researcher and include 6-8 young people joining in the discussion.

If they are happy to take part in the research, the focus group will take place via MS Teams at a time that is convenient to them. The focus group should take approximately 40-60 minutes. It is important the focus group is confidential, and therefore please ensure your child has access to a safe, quiet space before joining. Any member of the focus group can ask to pause or stop the focus group at any time. They may choose to do this if they feel uncomfortable or compromised. For children between 13-15 years we will require both a participant assent form (signed by the child) and a parent consent form (signed by a parent/guardian) before they can participate. With your and your child's consent, we would like to audio record the focus group so we can have an accurate record of their thoughts.

Online Survey: If they would prefer to complete an online survey you will be sent a link to do so. The survey should take approximately 10-15 minutes. At the end of the survey we will ask if they would like to also talk to us by telephone. This is optional.

The focus of the focus group/interview/survey will be on their experiences of sensory input. We will ask about any discomfort or preferences for particular sensory inputs, and the ways they cope with these experiences. We will also ask about what they think would be important to include in the questionnaire.

They/you will have an opportunity to ask any questions about the study and you will then both be asked to sign a consent form. Once received, you will either be sent a link to the online survey, or to the focus group/interview.

5. Are there any potential risks in taking part?

If they do decide to take part in the focus group/interview, we will be asking your child to share their experiences with the group. It is possible that confidentiality may be broken. We will ask everyone to not share what they have heard in the group with other people. This will make sure what is shared will be kept private. Their information and what they say will be pseudonymised. This means their name will be changed in the written records to reduce the chance of them being identified.

If your child becomes upset or they want to discuss anything outside of the group setting, please feel free to contact Eloise Maguire on eloise.ainger@hmc.ox.ac.uk.

Alternatively, if they feel they need to speak with someone for support, please see below for details of how to do so:

- Call 111 for the 24/7 Mental Health Helpline
- Call Samaritans (116 123) any time of day for free confidential support

You may find further information and helpful tools on the following websites:

- Oxford Health CAMHS website: https://www.oxfordhealth.nhs.uk/camhs/self-care/
- YoungMinds website: https://www.youngminds.org.uk

6. Are there any benefits in taking part?

There will be no direct or personal benefit from taking part in this research. We hope that this study however will lead to a measure that can be used by different professionals to help us understand how different people manage their sensory experiences. The child will be provided with a monetary voucher for their time.

7. How will we use information about you?

We will need to use information from you and your child for this research project.

This information will include:

- Your name
- Child's name
- Contact details
- Child's age range

- Child's gender
- Child's ethnicity
- Any diagnoses your child has related to sensory sensitivities

We will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who your child is will not be able to see their name or contact details. Your child's data will have a code number instead.

We will keep all information about your child safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that your child took part in the study.

Your child can stop being part of the study at any time, without giving a reason, but we will keep information about them that we already have. We need to manage your child's records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about your child.

A document linking your child's data to their pseudo ID will be kept in a password protected document only accessible to the researcher. All data, including audio recordings and transcriptions will be stored electronically on an encrypted password protected NHS computer and a secure service One Drive. Recordings will be destroyed after being transcribed by the researcher. Data will only be seen by the researcher and supervisors. This information will be kept for three years and then will be destroyed.

Other research data (including consent forms) will be stored for 10 after publication or public release of the work of the research. The researcher and supervisors will have access to the research data. Responsible members of the sponsor's representative may be given access to data for monitoring and/or audit of the research. We would like your permission to use direct quotes against a made-up name in any research outputs.

8. Where can you find out more about how your information is used?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- our leaflet available from https://www.oxfordhealth.nhs.uk/privacy/
- by asking or contacting one of the research team [eloise.ainger@hmc.ox.ac.uk]

- by sending an email to Oxford Health Data Protection Officer at mark.underwood@oxfordhealth.nhs.uk

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO) (www.ico.org or 0303 123 1113).

9. What will happen if my child doesn't want to carry on with the study?

Your child can stop being part of the study at any time, without giving a reason, but we may not be able to withdraw the information about them that we already have. We need to manage their records in specific ways for the research to be reliable. This means that we won't be able to let you or your child see or change the data we hold about them.

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

This study will be part of the researchers Clinical Psychology training. The results will be written up in a report and given to teachers and other students at the University. The report might also be published in a scientific journal. Your child will not be personally identified in the reports.

11. What if something goes wrong?

If you have any concerns about the way you have been approached or treated during the study, please talk to Eloise Maguire, Chief Investigator, Oxford Institute of Clinical Psychology Training and Research, Isis Education Centre, Warneford Hospital, Oxford, tel: 01865 226431, email: eloise.ainger@hmc.ox.ac.uk or Dr Myra Cooper: 01865 226431, myra.cooper@ox.ac.uk.

If you wish to speak to an independent body about any concerns or complaints about any aspect of the way you or your child have been approached or treated during this study, you can do this through the Patient Advice and Liaison Service (PALS). PALS, Oxford Health NHS Foundation Trust, PALS Office, Warneford Hospital, Warneford Lane, Oxford OX3 7JX. Tel: 0800 3287971. E-mail: PALS@oxfordhealth.nhs.uk

12. Who has reviewed this study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect participants' interests. This study has been reviewed and given favourable opinion by Hertfordshire and Cambridgeshire Research Ethics Committee

(22/EE/0031). This study has been also reviewed by, and received ethics clearance through, Oxford Health Foundation Trust.

13. Further Information and Contact Details

If you would like to discuss the research with someone beforehand (or if you have questions afterwards), please contact:

Eloise Maguire, Oxford Institute of Clinical Psychology Training and Research, Isis Education Centre, Warneford Hospital, Oxford.

University tel: 01865 226431, University email: eloise.ainger@hmc.ox.ac.uk

Appendix U: TDRP - Information Sheet – Young People Consultation Community Sample (13-15yrs)

Chief Investigator:
Eloise Maguire, Trainee Clinical Psychologist
Oxford Institute of Clinical Psychology Training and Research
eloise.ainger@hmc.ox.ac.uk

The Development of an Adolescent Sensory Coping Measure for use within Non-Clinical and Clinical Presentations

YOUNG PEOPLE CONSULTATION (13-15yrs) PARTICIPANT INFORMATION SHEET

We would like you to help us with our research study. Please read this information carefully and talk to your mum, dad or carer about the study. They also have some information to read. It is your choice if you want to take part. If you would like to take part, your parent will also need to sign a consent form.

1. Why are we doing this research?

We all experience "sensory input" all the time. Sensory input is when our senses are being used, such as sight, hearing, smell, taste, and touch. It can also be movement and the sense of our bodies. We all experience these things differently. For some people, sensory input (like noise and smells) are more difficult to process and manage. This can mean they might experience certain things more or less intensely than others. This can be uncomfortable for some.

At the moment, we don't have a good way of measuring how people manage sensory input. We are developing a questionnaire that will help us understand how people manage sensory experiences. First, we would like to speak to young people experiencing sensory sensitivity. This will help us decide on the questions for the questionnaire. We will then talk to a group of experts. Once the questionnaire is complete, we will ask young people to complete it. We will

then finalise the questionnaire and ask autistic individuals and individuals who have experienced difficult life experiences to complete the questionnaire. This will tell us if there are any differences in the way they manage sensory input.

You are being invited to take part in talking to us about your sensory experiences. You will have the option to take part in an interview or focus group, or to complete an online survey.

2. Why have I been invited to take part?

You have been invited because you are between the ages of 13-18 years and have an autism diagnosis and/or have experienced stressful events growing up. You may have some experience of finding sensory input difficult and may use different methods to help.

3. Do I have to take part?

No. You can ask questions about the research before deciding whether or not to take part. If you do agree to take part, you can stop at any time by telling us. You do not have to tell us why.

4. What will happen to me if I take part in the research?

You may choose how you would like to take part, either through attending a focus group, interview, or completing an online survey.

Focus groups/interviews: You will be asked to attend 1 focus group/interview session which will take place online. A focus group is a group of people discussing a topic together. Around 6-8 young people will be there to join in the discussion. If you choose to attend an interview, you will meet with one researcher only. A researcher will ask questions.

The focus group/interview/survey will take place online. What you share is private. If joining a focus group or interview, you should be in a safe, quiet space. The focus group will take around 40-60 minutes. You can also ask to pause or stop the focus group at any time. You may choose to do this if you feel uncomfortable, or you are no longer in a safe space. With your consent, we would like to audio record you so we can have an accurate record of your thoughts.

Online Survey: If you would prefer to complete an online survey you will be sent a link to do so. The survey should take approximately 10-15 minutes. At the end of the survey we will ask if you would like to also talk to us by telephone. This is optional.

We will ask you about your experiences of sensory input. We will ask about any sensory inputs you like or don't like, and what you do when you experience them. We will also ask you about what you think should be in the questionnaire.

If you are happy to take part, I will ask you to complete an assent form. A parent or carer will also need to read their information sheet and complete a parent consent form to say they agree for you to take part. You will have a chance to ask any questions before the focus group begins.

5. Is there anything to worry about if I take part?

If you decide to take part in the focus group we will ask you to share your experiences with the group. It is possible that others in the group may share what you say with other people. We will ask everyone in the group to not do this. This will make sure what you share will be kept private. The information you give us will be given a code. We won't use your name in the written reports to reduce the chance of you being recognised.

If you become upset or want to discuss anything outside of the group setting, you or your parents/carer can contact Eloise Maguire on eloise.ainger@hmc.ox.ac.uk.

Alternatively, if you feel you need to speak with someone for support, please see below for details of how to do so:

- Call 111 for the 24/7 Mental Health Helpline
- Call Samaritans (116 123) any time of day for free confidential support

You may find further information and helpful tools on the following websites:

- Oxford Health CAMHS website: https://www.oxfordhealth.nhs.uk/camhs/self-care/
- YoungMinds website: https://www.youngminds.org.uk

It can be helpful to discuss how you are feeling with someone you know and trust. This may be a parent, teacher, school nurse, friend, family member, GP or other professional.

6. Are there any benefits in taking part?

This study will not directly help you but the information you provide will help us create a questionnaire. We hope this can be used by professionals to help understand how different people manage their sensory experiences. This will enable them to know how to help. You will also be provided with a voucher.

7. How will we use information about you?

We will need to use information from you for this research project.

This information will include your:

- Name
- Contact details
- Age range
- Gender
- Ethnicity
- Any diagnoses related to sensory sensitivities

We will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

We will keep a document that links your code and your information. This document will be kept secure and private. Only the researcher will access this. After we type up what was said in the focus group, the recording will be deleted. Data will only be seen by the researcher and supervisors. This information will be kept for three years and then will be destroyed.

Other research data (including consent forms) will be kept for 10 years after publication. Only the researcher and supervisors will have access to the research data. It may also be shared with a sponsor's representative.

8. Where can you find out more about how your information is used?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/

- our leaflet available from https://www.oxfordhealth.nhs.uk/privacy/
- by asking or contacting one of the research team [eloise.ainger@hmc.ox.ac.uk]
- by sending an email to Oxford Health Data Protection Officer at mark.underwood@oxfordhealth.nhs.uk

If you want to make a complaint about how we handled your personal information, you or your parents/carers can contact our Data Protection Officer. If you are not happy with our response you can complain to the Information Commissioner's Office (ICO) (www.ico.org or 0303 123 1113).

9. What will happen if I don't want to carry on with the study?

You can stop being part of the study at any time. You do not have to tell us why. We may not be able to withdraw the information about you that we already have. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

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

This study will be part of the researchers Clinical Psychology training. The results will be written up in a report and given to teachers and other students at the University. The report might also be published in a scientific magazine. You will not be personally identified in the reports. This means that you can't be recognised in the reports.

11. What if something goes wrong?

If you or your parents/carers have any worries about the way you were treated during the study, please talk to Eloise Maguire, Chief Investigator, Oxford Institute of Clinical Psychology Training and Research, Isis Education Centre, Warneford Hospital, Oxford, tel: 01865 226431, email: eloise.ainger@hmc.ox.ac.uk or Dr Myra Cooper: 01865 226431, myra.cooper@ox.ac.uk

If you would like to speak to someone outside of the study about any concerns or complaints, you can do this through the Patient Advice and Liaison Service (PALS). PALS, Oxford Health NHS Foundation Trust, PALS Office, Warneford Hospital, Warneford Lane, Oxford OX3 7JX. Tel: 0800 3287971. E-mail: PALS@oxfordhealth.nhs.uk

12. Who has reviewed this study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect participants' interests. This study has been reviewed and given favourable opinion by Hertfordshire and Cambridgeshire Research Ethics Committee (22/EE/0031). This study has been also reviewed by, and received ethics clearance through, Oxford Health Foundation Trust.

13. Further Information and Contact Details

If you would like to discuss the research with someone beforehand (or if you have questions afterwards), please contact:

Eloise Maguire, Oxford Institute of Clinical Psychology Training and Research, Isis Education Centre, Warneford Hospital, Oxford.

University tel: 01865 226431, University email: eloise.ainger@hmc.ox.ac.uk

Appendix V: TDRP - Information Sheet – Young People Consultation Community Sample (16-18yrs)

Chief Investigator:
Eloise Maguire, Trainee Clinical Psychologist
Oxford Institute of Clinical Psychology Training and Research
eloise.ainger@hmc.ox.ac.uk

The Development of an Adolescent Sensory Coping Measure for use within Non-Clinical and Clinical Presentations

YOUNG PEOPLE CONSULTATION (16-18yrs)
PARTICIPANT INFORMATION SHEET

1. Why is this research being conducted?

We all experience "sensory input" all the time. Sensory input is when our senses are being used, such as when we are looking at something, hearing a noise, smelling something, taste, and touch. It can also be movement and the sense of our bodies. We all experience these things differently. For some people, sensory input (like noise and smells) are more difficult to process and manage. For example, for some autistic individuals and some people who have had difficult things happen in their life. These individuals also share a lot of other common features. This can make it harder for professionals to diagnose correctly and help them in the most appropriate way. We think that the way they manage sensory input might be one way they differ.

At the moment, we don't have a good way of measuring how people manage sensory input as there are no questionnaires that look at this. This study therefore aims to develop a questionnaire that will help us understand how people generally manage sensory input or experiences. First, we would like to speak to young people experiencing sensory sensitivity. This will help us develop the questions for the questionnaire. We will then also ask a group of experts. Once the questionnaire is complete, we will ask young people to complete it. We will then finalise the questionnaire and ask autistic individuals and individuals who have experienced difficult life experiences to complete the questionnaire. This will tell us if there are any differences in the way they manage sensory input.

You are being invited to take part in talking to us about your sensory experiences. You will have the option to take part in an interview or focus group, or to complete an online survey.

2. Why have I been invited to take part?

You have been invited because you are between the ages of 13-18 years and have an autism diagnosis and/or have experienced stressful events growing up. You may have some experience of finding sensory input difficult and may use different methods to help.

3. Do I have to take part?

No. You can ask questions about the research before deciding whether or not to take part. If you do agree to take part, you can stop at any time by telling us. You do not have to tell us why.

4. What will happen to me if I take part in the research?

You may choose how you would like to take part, either through attending a focus group, interview, or completing an online survey.

Focus groups/interviews: You will be asked to attend 1 focus group/interview session which will take place online. This will be led by the researcher and include 6-8 young people joining in the discussion. The conversation will be focused on your experiences of sensory input. If you choose to attend an interview, you will meet with one researcher only.

The focus group/interview will take place via MS Teams at a time that is convenient to you. The focus group is confidential. You should take care to ensure you are in a safe, quiet space before joining the focus group. The focus group should take approximately 40-60 minutes. You can also ask to pause or stop the focus group at any time. You may choose to do this if you feel uncomfortable, or you are no longer in a safe space, away from others. With your consent, we would like to audio record you so we can have an accurate record of your thoughts.

Online Survey: If you would prefer to complete an online survey you will be sent a link to do so. The survey should take approximately 10-15 minutes. At the end of the survey we will ask if you would like to also talk to us by telephone. This is optional.

During the interview/focus group/survey, we will ask about any discomfort or preferences for particular sensory inputs, and the ways you cope with these experiences. We will also ask you about what you think would be important to include in the questionnaire.

You will have an opportunity to ask any questions about the study and will then be asked to sign a consent form. Once received, you will either be sent a link to the online survey, or to the focus group/interview.

5. Are there any potential risks in taking part?

If you decide to take part in the focus group we are asking you to share your experiences with the group. It is possible that confidentiality may be broken. We will ask everyone to not share what they have heard in the group with other people. This will make sure what you share will be kept private. Your information and what you say will be pseudonymised. This means your name will be changed in the written records to reduce the chance of you being identified.

If you become upset or want to discuss anything outside of the group setting, please feel free to contact Eloise Maguire on eloise.ainger@hmc.ox.ac.uk.

Alternatively, if you feel you need to speak with someone for support, please see below for details of how to do so:

- Call 111 for the 24/7 Mental Health Helpline
- Call Samaritans (116 123) any time of day for free confidential support

You may find further information and helpful tools on the following websites:

- Oxford Health CAMHS website: https://www.oxfordhealth.nhs.uk/camhs/self-care/
- YoungMinds website: https://www.youngminds.org.uk

It can be helpful to discuss how you are feeling with someone you know and trust. This may be a parent, teacher, school nurse, friend, family member, GP or other professional.

6. Are there any benefits in taking part?

There will be no direct or personal benefit to you from taking part in this research. We hope that this study however will lead to a measure that can be used by different professionals to help us understand how different people manage their sensory experiences. You will be provided with a monetary voucher.

7. How will we use information about you?

We will need to use information from you for this research project.

This information will include your:

- Name
- Contact details

- Age range
- Gender
- Ethnicity
- Any diagnoses related to sensory sensitivities

We will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

A document linking your code to your data will be kept in a password protected document and only the researcher will be able to access this. All data, including audio recordings and transcriptions will be stored electronically on an encrypted password protected NHS computer and a secure service One Drive. Recordings will be destroyed after being transcribed by the researcher. Data will only be seen by the researcher and supervisors. This information will be kept for three years and then will be destroyed.

Other research data (including consent forms) will be stored for 10 years after publication or public release of the work of the research. The researcher and supervisors will have access to the research data. Responsible members of the sponsor's representative may be given access to data for monitoring and/or audit of the research. We would like your permission to use direct quotes against a made-up name in any research outputs.

8. Where can you find out more about how your information is used?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/

- our leaflet available from https://www.oxfordhealth.nhs.uk/privacy/
- by asking or contacting one of the research team [eloise.ainger@hmc.ox.ac.uk]
- by sending an email to Oxford Health Data Protection Officer at mark.underwood@oxfordhealth.nhs.uk

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO) (www.ico.org or 0303 123 1113).

9. What will happen if I don't want to carry on with the study?

You can stop being part of the study at any time, without giving a reason, but we may not be able to withdraw the information about you that we already have. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

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

This study will be part of the researchers Clinical Psychology training. The results will be written up in a report and given to teachers and other students at the University. The report might also be published in a scientific magazine. You will not be personally identified in the reports.

11. What if something goes wrong?

If you have any concerns about the way you have been approached or treated during the study, please talk to, Eloise Maguire, Chief Investigator, Oxford Institute of Clinical Psychology Training and Research, Isis Education Centre, Warneford Hospital, Oxford, tel: 01865 226431, email: eloise.ainger@hmc.ox.ac.uk or Dr Myra Cooper: 01865 226431, myra.cooper@ox.ac.uk

If you wish to speak to an independent body about any concerns or complaints about any aspect of the way you have been approached or treated during this study, you can do this through the Patient Advice and Liaison Service (PALS). PALS, Oxford Health NHS Foundation Trust, PALS Office, Warneford Hospital, Warneford Lane, Oxford OX3 7JX. Tel: 0800 3287971. E-mail: PALS@oxfordhealth.nhs.uk

12. Who has reviewed this study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect participants' interests. This study has been reviewed and given favourable opinion by Hertfordshire and Cambridgeshire Research Ethics Committee (22/EE/0031). This study has been also reviewed by, and received ethics clearance through, Oxford Health Foundation Trust.

13. Further Information and Contact Details

If you would like to discuss the research with someone beforehand (or if you have questions afterwards), please contact:

Eloise Maguire, Oxford Institute of Clinical Psychology Training and Research, Isis Education Centre, Warneford Hospital, Oxford.

University tel: 01865 226431, University email: eloise.ainger@hmc.ox.ac.uk

Appendix W: TDRP - Information Sheet – Young People Consultation Community Sample (parent)

Chief Investigator:
Eloise Maguire, Trainee Clinical Psychologist
Oxford Institute of Clinical Psychology Training and Research
eloise.ainger@hmc.ox.ac.uk

The Development of an Adolescent Sensory Coping Measure for use within Non-Clinical and Clinical Presentations

YOUNG PEOPLE CONSULTATION PARENT INFORMATION SHEET

1. Why is this research being conducted?

We all experience "sensory input" (e.g. sight, sounds, smells, tastes, touch, movement) differently. For some people, such as autistic individuals or those who have experienced trauma, sensory input is more difficult to process and manage. These individuals also share a lot of other key features which can lead to misdiagnosis and difficulties being missed. It is possible however, that these two groups may differ in the way they manage their sensory experiences.

At the moment, we don't have a good way of measuring how people manage sensory input. This study therefore aims to develop a questionnaire that will help us understand how people generally manage sensory input or experiences.

Questionnaire items will be developed through literature searching, speaking with young people experiencing sensory sensitivities, and a focus group with experts in the field. The questionnaire will then be rolled out to the general population of 13–18-year-olds. Following the finalisation of the questionnaire, young autistic individuals and individuals who have experienced interpersonal trauma will complete the final measure to explore any differences.

Your child is being invited to take part talking to use about their sensory experiences. They will have the option to take part in an interview or focus group, or to complete an online survey.

We will then ask autistic individuals and individuals who have experienced difficult life experiences to complete the questionnaire, which will tell us if there are any differences in the way they manage sensory input.

2. Why has my child been invited to take part?

Your child has been invited to take part because they are between the ages of 13-18 years and have an autism diagnosis and/or have experienced stressful events growing up. They may also have some experience of finding sensory input difficult and may use different methods to help.

3. Do they have to take part?

No. You and your child can ask questions about the research before deciding whether or not to take part. If you do agree to take part, they can stop at any time by telling us and without giving a reason.

4. What will happen to my child if they take part in the research?

Your child may choose how they would like to take part, either through attending a focus group, interview, or completing an online survey.

Focus groups/interviews: Your child will be asked to attend 1 focus group/interview session which will take place online. This will be led by the researcher and include 6-8 young people joining in the discussion.

If they are happy to take part in the research, the focus group will take place via MS Teams at a time that is convenient to them. The focus group should take approximately 40-60 minutes. It is important the focus group is confidential, and therefore please ensure your child has access to a safe, quiet space before joining. Any member of the focus group can ask to pause or stop the focus group at any time. They may choose to do this if they feel uncomfortable or compromised. For children between 13-15 years we will require both a participant assent form (signed by the child) and a parent consent form (signed by a parent/guardian) before they can participate. With your and your child's consent, we would like to audio record the focus group so we can have an accurate record of their thoughts.

Online Survey: If they would prefer to complete an online survey you will be sent a link to do so. The survey should take approximately 10-15 minutes. At the end of the survey we will ask if they would like to also talk to us by telephone. This is optional.

The focus of the focus group/interview/survey will be on their experiences of sensory input. We will ask about any discomfort or preferences for particular sensory inputs, and the ways

they cope with these experiences. We will also ask about what they think would be important to include in the questionnaire.

They/you will have an opportunity to ask any questions about the study and you will then both be asked to sign a consent form. Once received, you will either be sent a link to the online survey, or to the focus group/interview.

5. Are there any potential risks in taking part?

If they do decide to take part in the focus group/interview, we will be asking your child to share their experiences with the group. It is possible that confidentiality may be broken. We will ask everyone to not share what they have heard in the group with other people. This will make sure what is shared will be kept private. Their information and what they say will be pseudonymised. This means their name will be changed in the written records to reduce the chance of them being identified.

If your child becomes upset or they want to discuss anything outside of the group setting, please feel free to contact Eloise Maguire on eloise.ainger@hmc.ox.ac.uk.

Alternatively, if they feel they need to speak with someone for support, please see below for details of how to do so:

- Call 111 for the 24/7 Mental Health Helpline
- Call Samaritans (116 123) any time of day for free confidential support

You may find further information and helpful tools on the following websites:

- Oxford Health CAMHS website: https://www.oxfordhealth.nhs.uk/camhs/self-care/
- YoungMinds website: https://www.youngminds.org.uk

6. Are there any benefits in taking part?

There will be no direct or personal benefit from taking part in this research. We hope that this study however will lead to a measure that can be used by different professionals to help us understand how different people manage their sensory experiences. The child will be provided with a monetary voucher for their time.

7. How will we use information about you?

We will need to use information from you and your child for this research project.

This information will include:

- Your name

- Child’s name
- Contact details
- Child’s age range
- Child's gender
- Child’s ethnicity
- Any diagnoses your child has related to sensory sensitivities

We will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who your child is will not be able to see their name or contact details. Your child’s data will have a code number instead.

We will keep all information about your child safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that your child took part in the study.

Your child can stop being part of the study at any time, without giving a reason, but we will keep information about them that we already have. We need to manage your child’s records in specific ways for the research to be reliable. This means that we won’t be able to let you see or change the data we hold about your child.

A document linking your child’s data to their pseudo ID will be kept in a password protected document only accessible to the researcher. All data, including audio recordings and transcriptions will be stored electronically on an encrypted password protected NHS computer and a secure service One Drive. Recordings will be destroyed after being transcribed by the researcher. Data will only be seen by the researcher and supervisors. This information will be kept for three years and then will be destroyed.

Other research data (including consent forms) will be stored for 10 after publication or public release of the work of the research. The researcher and supervisors will have access to the research data. Responsible members of the sponsor’s representative may be given access to data for monitoring and/or audit of the research. We would like your permission to use direct quotes against a made-up name in any research outputs.

8. Where can you find out more about how your information is used?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- our leaflet available from https://www.oxfordhealth.nhs.uk/privacy/
- by asking or contacting one of the research team [eloise.ainger@hmc.ox.ac.uk]
- by sending an email to Oxford Health Data Protection Officer at mark.underwood@oxfordhealth.nhs.uk

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO) (www.ico.org or 0303 123 1113).

9. What will happen if my child doesn't want to carry on with the study?

Your child can stop being part of the study at any time, without giving a reason, but we may not be able to withdraw the information about them that we already have. We need to manage their records in specific ways for the research to be reliable. This means that we won't be able to let you or your child see or change the data we hold about them.

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

This study will be part of the researchers Clinical Psychology training. The results will be written up in a report and given to teachers and other students at the University. The report might also be published in a scientific journal. Your child will not be personally identified in the reports.

11. What if something goes wrong?

If you have any concerns about the way you have been approached or treated during the study, please talk to Eloise Maguire, Chief Investigator, Oxford Institute of Clinical Psychology Training and Research, Isis Education Centre, Warneford Hospital, Oxford, tel: 01865 226431, email: eloise.ainger@hmc.ox.ac.uk or Dr Myra Cooper: 01865 226431, myra.cooper@ox.ac.uk.

If you wish to speak to an independent body about any concerns or complaints about any aspect of the way you or your child have been approached or treated during this study, you can do this through the Patient Advice and Liaison Service (PALS). PALS, Oxford Health NHS Foundation Trust, PALS Office, Warneford Hospital, Warneford Lane, Oxford OX3 7JX. Tel: 0800 3287971. E-mail: PALS@oxfordhealth.nhs.uk

12. Who has reviewed this study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect participants' interests. This study has been reviewed and given favourable opinion by Hertfordshire and Cambridgeshire Research Ethics Committee (22/EE/0031). This study has been also reviewed by, and received ethics clearance through, Oxford Health Foundation Trust.

13. Further Information and Contact Details

If you would like to discuss the research with someone beforehand (or if you have questions afterwards), please contact:

Eloise Maguire, Oxford Institute of Clinical Psychology Training and Research, Isis Education Centre, Warneford Hospital, Oxford.

University tel: 01865 226431, University email: eloise.ainger@hmc.ox.ac.uk

Appendix X: TDRP – Email Advertisement - Young People Consultation CAMHS Sample

Dear [team],

I am currently conducting a study alongside Dr James Stacey and Dr Carmen Chan to develop a new adolescent sensory modulation questionnaire and are recruiting young people to be involved in its development! I wondered if you might be able to pass this on to your colleagues and young people if possible, please?

This research has derived from the ongoing difficulty distinguishing between ASD and developmental trauma due to their many similar features. We hope this measure may begin to help us understand any possible differences related to sensory modulation between these two groups, and for this measure to be useful for all CAMHS services.

We would love to get young people's views on the new measure and therefore are recruiting young people between the ages of 13-18 years who have sensory sensitivities and either a diagnosis of autism and/or have experienced developmental trauma.

If you are currently working any young people that meet the above criteria, we would be really grateful if you could pass on the information and consent form to them/their parents via the below links:
They will receive a £7.50 for taking part

- ***Service users ages 16-18yrs:*** https://psychiatryoxford.qualtrics.com/jfe/form/SV_299XsU0oS1O0Swe
- ***Service users aged 13-15yrs: (please provide both child and parent links)***
  - ***YP:*** https://psychiatryoxford.qualtrics.com/jfe/form/SV_afUiLD6bayB9qwC
  - ***Parent:*** https://psychiatryoxford.qualtrics.com/jfe/form/SV_9WV0gTwb5vubpX0

We are giving young people the option regarding how they would like to take part. They can either:

- Complete an online survey (approx. 15mins of their time)
- **OR** Attend a focus group (approx. 60mins of their time)
- **OR** Attend an interview (approx. 45mins of their time)

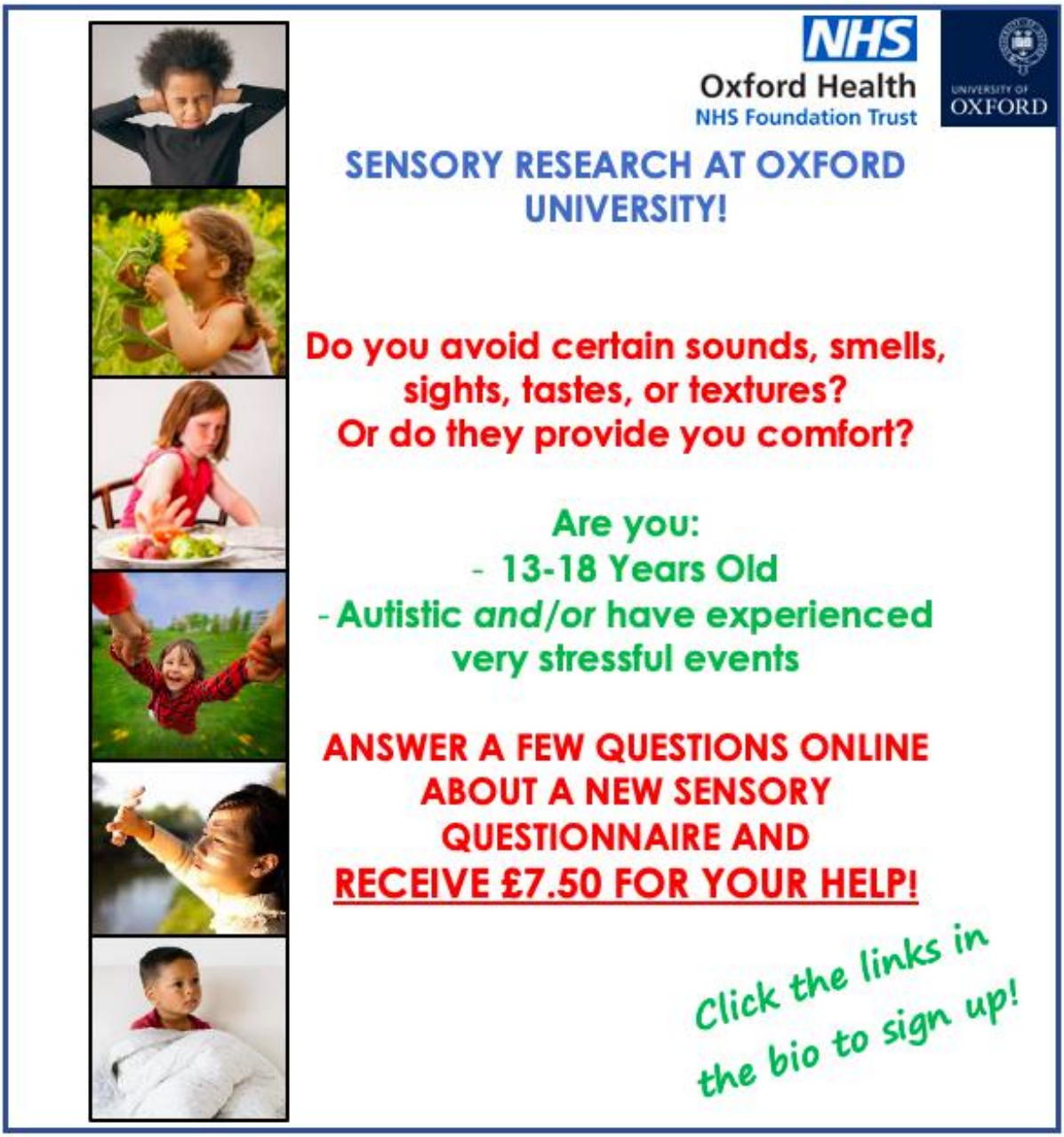
I have also attached a separate poster with the QR codes to share with young people if this is easier.

If they choose to take part in the online survey, this will be sent to them after consent is provided.
They may also choose to email me on [email address].

Many thanks for your help. Please do not hesitate to get back to me if you would like to discuss further.

Best wishes,
[Trainee]

Appendix Y: TDRP - Social Media Advertisement - Young People Consultation Community Sample



Appendix Z: TDRP - Consent Form – Young People Consultation CAMHS Sample (13-15yrs)

Chief Investigator:
Eloise Maguire, Trainee Clinical Psychologist
Oxford Institute of Clinical Psychology Training and Research
eloise.ainger@hmc.ox.ac.uk

SERVICE USER FOCUS GROUP/ONLINE SURVEY 13-15yrs
PARTICIPANT ASSENT FORM

IRAS Reference: 289550

The Development of an Adolescent Sensory Coping Measure for use within Non-Clinical and Clinical Presentations

If you would like to take part in talking with us about your sensory experiences, please complete the consent form below.

Please tick each box

1 I confirm that I have read and understand the information sheet version 3 dated 25/05/2022 for the above study. I have had a chance to think about the information, ask questions and have had these answered. ☐

2 I understand that I do not have to take part in the focus group/interview or survey and that it is my choice. I know that I can stop at any time without telling us why. I understand that participating or not participating in the study will not affect my CAMHS support in any way. ☐

3 I understand that the data/my responses collected during the study may be looked at by other people outside the research team. For example, Eloise Maguire and staff that support Eloise Maguire. These people will never be people I know. My family, friends and teachers will not see it. ☐

4 I understand who will have access to personal data provided (including name, email address, age, gender, ethnicity and diagnoses related to sensory sensitivities), how the data will be stored and what will happen to the data at the end of the project. ☐

5 I agree to audio recording (focus groups/interviews only) and that a written version of what was discussed can be put into research reports and publications. Specific quotes, my name or other information about me will not be included. ☐

6 I agree to take part in the study

Name _____ Date_____ Email address (We will use this to send to send you a link to the focus group/interview, and/or online survey): _____
Researcher signature: _____ Date: _____
We will send a signed copy of this consent form to the email address you gave us. The research team will also keep a copy of this form.

Appendix AA: TDRP - Consent Form – Young People Consultation CAMHS Sample (16-18yrs)

Chief Investigator:
Eloise Maguire, Trainee Clinical Psychologist
Oxford Institute of Clinical Psychology Training and Research
eloise.ainger@hmc.ox.ac.uk

SERVICE USER FOCUS GROUP 16-18yrs PARTICIPANT CONSENT FORM

IRAS Reference: 289550

The Development of an Adolescent Sensory Coping Measure for use within Non-Clinical and Clinical Presentations

If you would like to take part in talking with us about your sensory experiences, please complete the consent form below.

Please tick each box

1	I confirm that I have read and understand the information sheet version 4 dated 25/05/2022 for the above study. I have had a chance to think about the information, ask questions and have had these answered.	☐
2	I understand that I do not have to take part in the focus group/interview or survey and that it is my choice. I know that I can stop at any time without telling us why. I understand that participating or not participating in the study will not affect my CAMHS support in any way.	☐
3	I understand that the data/my responses collected during the study may be looked at by other people outside the research team. For example, Eloise Maguire and staff that support Eloise Maguire. These people will never be people I know. My family, friends and teachers will not see it.	☐
4	I understand who will have access to personal data provided, (including name, email address, age, gender, ethnicity and diagnoses related to sensory sensitivities), how the data will be stored and what will happen to the data at the end of the project.	☐
5	I agree to audio recording (focus groups and interviews only) and that a written version of what was discussed can be put into research reports and publications. Specific quotes, my name or other information about me will not be included.	☐
6	I agree to take part in the study	

Name _____ Date_____Email address (We will use this to send to send you a link to the focus group/interview, and/or online survey): _____
Researcher signature: _____ Date:

A signed copy of this consent form will be sent to you via email. The research team will also keep a copy of this form.

Appendix BB: TDRP - Consent Form – Young People Consultation CAMHS Sample (parent)

Chief Investigator:
Eloise Maguire, Trainee Clinical Psychologist
Oxford Institute of Clinical Psychology Training and Research
eloise.ainger@hmc.ox.ac.uk

SERVICE USER FOCUS GROUP/ONLINE SURVEY PARENT CONSENT FORM

IRAS Reference: 289550

The Development of an Adolescent Sensory Coping Measure for use within Non-Clinical and Clinical Presentations

If you are happy for your child to take part in talking with us about their sensory experiences, please complete the consent form below.

Please tick each box

1	I confirm that I have read and understand the parent information sheet version 4 dated 25/05/2022 for the above study. I have had a chance to consider the information, ask questions and have had these answered satisfactorily.	☐
2	I understand that my child's participation is voluntary and that they are free to withdraw at any time, without giving any reason, and without any adverse consequences or penalty.	☐
3	I understand that research data collected during the study may be looked at by authorised people outside the research team. I give permission for these individuals to access my child's data.	☐
4	I understand who will have access to personal data provided (including name, email address, age, gender, ethnicity and diagnoses related to sensory sensitivities), how the data will be stored and what will happen to the data at the end of the project.	☐
5	I agree to audio recording (focus groups/interviews only) and the general themes of our discussions to be included in research reports and publications. No individual quotes will be published.	☐
6	I agree for my child to take part in the study.	☐

Name _____ Name of child _____ Date_____
Email address (We will use this to send to send you a link to the focus group/interview, and/or online survey): _____
Researcher signature: _____ Date:

A signed copy of this consent form will be sent to you via email. The research team will also keep a copy of this form.

Appendix CC: TDRP - Consent Form – Young People Consultation Community Sample (13-15yrs)

Chief Investigator:
Eloise Maguire, Trainee Clinical Psychologist
Oxford Institute of Clinical Psychology Training and Research
eloise.ainger@hmc.ox.ac.uk

YOUNG PEOPLE CONSULTATION 13-15yrs PARTICIPANT ASSENT FORM

IRAS Reference: 289550

The Development of an Adolescent Sensory Coping Measure for use within Non-Clinical and Clinical Presentations

If you would like to take part in talking with us about your sensory experiences, please complete the consent form below.

		Please tick each box
1	I confirm that I have read and understand the information sheet version 4 dated 18/07/2022 for the above study. I have had a chance to think about the information, ask questions and have had these answered.	☐
2	I understand that I do not have to take part in the focus group/interview or survey and that it is my choice. I know that I can stop at any time without telling us why.	☐
3	I understand that the data/my responses collected during the study may be looked at by other people outside the research team. For example, Eloise Maguire and staff that support Eloise Maguire. These people will never be people I know. My family, friends and teachers will not see it.	☐
4	I understand who will have access to personal data provided (including name, email address, age, gender, ethnicity and diagnoses related to sensory sensitivities), how the data will be stored and what will happen to the data at the end of the project.	☐
5	I agree to audio recording (focus groups/interviews only) and that a written version of what was discussed can be put into research reports and publications. Specific quotes, my name or other information about me will not be included.	☐
6	I agree to take part in the study	

Name _____ Date_____ Email address (We will use this to send to send you a link to the focus group/interview, and/or online survey): _____
Researcher signature: _____ Date:

We will send a signed copy of this consent form to the email address you gave us. The research team will also keep a copy of this form.

Appendix DD: TDRP - Consent Form – Young People Consultation Community Sample (16-18yrs)

Chief Investigator:
Eloise Maguire, Trainee Clinical Psychologist
Oxford Institute of Clinical Psychology Training and Research
eloise.ainger@hmc.ox.ac.uk

YOUNG PEOPLE CONSULTATION 16-18yrs PARTICIPANT CONSENT FORM

IRAS Reference: 289550

The Development of an Adolescent Sensory Coping Measure for use within Non-Clinical and Clinical Presentations

If you would like to take part in talking with us about your sensory experiences, please complete the consent form below.

Please tick each box

1	I confirm that I have read and understand the information sheet version 5 dated 18/07/2022 for the above study. I have had a chance to think about the information, ask questions and have had these answered.	☐
2	I understand that I do not have to take part in the focus group/interview or survey and that it is my choice. I know that I can stop at any time without telling us why.	☐
3	I understand that the data/my responses collected during the study may be looked at by other people outside the research team. For example, Eloise Maguire and staff that support Eloise Maguire. These people will never be people I know. My family, friends and teachers will not see it.	☐
4	I understand who will have access to personal data provided, (including name, email address, age, gender, ethnicity and diagnoses related to sensory sensitivities), how the data will be stored and what will happen to the data at the end of the project.	☐
5	I agree to audio recording (focus groups and interviews only) and that a written version of what was discussed can be put into research reports and publications. Specific quotes, my name or other information about me will not be included.	☐
6	I agree to take part in the study	

Name _____ Date_____ Email address (We will use this to send to send you a link to the focus group/interview, and/or online survey): _____
Researcher signature: _____ Date:
A signed copy of this consent form will be sent to you via email. The research team will also keep a copy of this form.

Appendix EE: TDRP - Consent Form – Young People Consultation Community Sample (parent)

Chief Investigator:
Eloise Maguire, Trainee Clinical Psychologist
Oxford Institute of Clinical Psychology Training and Research
eloise.ainger@hmc.ox.ac.uk

YOUNG PEOPLE CONSULTATION PARENT CONSENT FORM

IRAS Reference: 289550

The Development of an Adolescent Sensory Coping Measure for use within Non-Clinical and Clinical Presentations

If you are happy for your child to take part in talking with us about their sensory experiences, please complete the consent form below.

Please tick each box

1	I confirm that I have read and understand the parent information sheet version 5 dated 18/07/2022 for the above study. I have had a chance to consider the information, ask questions and have had these answered satisfactorily.	☐
2	I understand that my child's participation is voluntary and that they are free to withdraw at any time, without giving any reason, and without any adverse consequences or penalty.	☐
3	I understand that research data collected during the study may be looked at by authorised people outside the research team. I give permission for these individuals to access my child's data.	☐
4	I understand who will have access to personal data provided (including name, email address, age, gender, ethnicity and diagnoses related to sensory sensitivities), how the data will be stored and what will happen to the data at the end of the project.	☐
5	I agree to audio recording (focus groups/interviews only) and the general themes of our discussions to be included in research reports and publications. No individual quotes will be published.	☐
6	I agree for my child to take part in the study.	☐

Name _____ Name of child _____ Date_____

Email address (We will use this to send to send you a link to the focus group/interview, and/or online survey): _____

Researcher signature: _____ Date:

A signed copy of this consent form will be sent to you via email. The research team will also keep a copy of this form.

Appendix FF: TDRP - Search Terms – Literature Searches

Search 1:

	"Sensory modulat*"
OR	"Management hypersensitiv*"
OR	"Sensory stimul*"
OR	Hypervigilen*
OR	Hyperarousal
AND	Healthy

Search 2:

	"Sensory modulat*"
OR	"Management hypersensitiv*"
OR	"Sensory stimul*"
OR	Hypervigilen*
OR	Hyperarousal
AND	autis*
OR	ASD

Search 3:

	"Sensory modulat*"
OR	"Management hypersensitiv*"
OR	"Sensory stimul*"
OR	Hypervigilen*
OR	Hyperarousal
AND	"Learning di*"

OR	“intellectual di*”

Search 4:

	“Sensory modulat*”
OR	“Management hypersensitiv*”
OR	“Sensory stimul*”
OR	Hypervigilen*
OR	Hyperarousal
AND	bipolar

Search 5:

	“Sensory modulat*”
OR	“Management hypersensitiv*”
OR	“Sensory stimul*”
OR	Hypervigilen*
OR	Hyperarousal
AND	ADHD
OR	Attention deficit?hyperactivity disorder

Search 6:

	“Sensory modulat*”
OR	“Management hypersensitiv*”
OR	“Sensory stimul*”
OR	Hypervigilen*
OR	Hyperarousal

AND	“eating disorder”
OR	anorexia
OR	bulimia

Search 7:

	“Sensory modulat*”
OR	“Management hypersensitiv*”
OR	“Sensory stimul*”
OR	Hypervigilen*
OR	Hyperarousal
AND	trauma
OR	“attachment disorder”
OR	PTSD
OR	ACES
OR	“Adverse event”

Appendix GG: TDRP - Item Pool – Questionnaire Development

Item list			
	Hypersensitivity		**Hyposensitivity**
1	Avoidance	1	Inattention
2	.. Covering ears	2	Distractability
3	.. Eye contact	3	Overfocused attention
4	.. Avoid textures	4	Impulsivity (jump from task to task)
5	.. Avoid noises	5	Withdrawing, not actively participating
6	.. Avoid busy places	6	Constant motion (rocking, bouncing, fidgetting, jumping, car rides, swinging, swimming)
7	.. Avoid certain movements	7	Weighted blankets/vests
8	.. Avoid unexpected touch	8	Walking into things
9	.. Avoid sand/water play	9	Rocking
10	.. Avoid food colours	10	Hand flapping
11	.. Avoid smells	11	Noise making
12	.. Somatic complaints	12	Jumping
13	.. Movements (feet leaving the ground - car rides, playground rides)	13	Banging
14	.. Sports (running, jumping etc)	14	Explore
15	Agitated, aggressive	15	Moving aimlessly
16	restlessness	16	Changing positions
17	Protecting self (e.g. arching away)	17	Dissociation/numbing
18	Crying	18	Music
19	Dissociation	19	Lotions
20	Numbing	20	Rhythmatic movements
21	Hypervigilence (impacting attention)	21	Touching others too often/hard
22	Apprehension/ fear	22	Touches/mouthes hair or objects
23	Food restrictions	23	Overactive, seeking movement
24	Over responding	24	Risky behaviour - climbing high/moving quickly
25	Switching focus	25	Bangs/taps body parts/objects
26	Defensiveness	26	Craves jumping/crashing activities
27	Withdrawal from others (due to sensitivity to tactile input)	27	Inappropriate movement and touch'
28	Withdrawal from activities	28	Compression
29	Screams/shouts	29	Muscle stretching
30	Self-injurious behaviour (hand biting, pulling ears)	30	Headbanging
31	Seeking predictable and less demanding environments	31	Pulling other people's hair
32	Pacing	32	Consistent movement/posture
33	Music	33	Passive - not modifying environment
		34	Sensory seeking

Appendix HH: TDRP - Demographic Survey - Experts Focus Group

Chief Investigator:
Eloise Maguire, Trainee Clinical Psychologist
Oxford Institute of Clinical Psychology Training and Research
eloise.ainger@hmc.ox.ac.uk

Participant ID (you will have been sent this in an email)

Profession/role

Age range:

- 18-24 years
- 25-34 years
- 35-44 years
- 45-54 years
- 55-64 years
- 65+ years

How do you describe yourself?

- Male
- Female
- Non-binary / third gender
- Prefer to self-describe
- Prefer not to say

Ethnicity

- White British
- White Irish
- Other White background
- Indian
- Pakistani
- Bangladeshi
- Chinese
- Other Asian background
- African
- Caribbean
- Other Black, African or Caribbean background
- Arab
- White and Black carribbean
- White and Black African
- White and Asian
- Other mixed ethnic background
- Other

Type of team you work in:

Number of years experience working with individuals with sensory sensitivities

- <1 year
- 1-3 years
- 4-6 years
- 7-9 years
- 10+ years

Appendix II: TDRP - Online Survey - Young People Consultation

Chief Investigator:
Eloise Maguire, Trainee Clinical Psychologist
Oxford Institute of Clinical Psychology Training and Research
eloise.ainger@hmc.ox.ac.uk

Your Experiences of Sensory Input

We'd like to ask about your experience of sensory inputs and how you cope with these. By sensory input, we mean anything that comes through our senses, the sensations you have and what you do about it, if anything. This includes things that we see, hear, touch/what we feel on our skin like clothes. It also includes tastes or textures when we eat or drink, smell, and also the different movements of our bodies.

We are asking you about this because there isn't a good questionnaire that helps us understand how you cope with sensory input. We want to create a questionnaire, so we are really interested to hear from you about your own experiences. This will help us to know what to include in our questionnaire.

We would also like to know what you think would be important to include in this questionnaire.

This survey should take about 10-15 minutes.

Thank you!

Before completing the survey, please provide some information about yourself:

Participant ID (you will have been sent this in an email)

Age range:

- 13-15 years old
- 16-18 years old

How do you describe yourself?

- Male
- Female
- Non-binary / third gender
- Prefer to self-describe
- Prefer not to say

Ethnicity

- White British
- White Irish
- Other White background
- Indian
- Pakistani
- Bangladeshi
- Chinese
- Other Asian background
- African
- Caribbean
- Other Black, African or Caribbean background
- Arab
- White and Black carribbean
- White and Black African
- White and Asian
- Other mixed ethnic background
- Other

Diagnoses (Please tick all that apply) that may impact your sensory experiences:

- Visual impairment
- Hearing impairment
- Autism Spectrum Disorder
- ADHD (Attention Deficit Hyperactivity Disorder)
- Sensory Processing Disorder
- Experienced 'trauma' or difficult life event
- Other
- I'm not sure
- Prefer not to say
- None of the above

Your sensory experiences:

Are there certain sensory inputs that you seek out or find calming or comforting?

Do you notice you go to find certain things when you feel worried or unsettled?

- Certain sounds
- Certain smells
- Certain tastes
- Things I can touch (like clothing or certain textures)
- Things I see (like bright lights etc)
- Certain movements (like car rides)

Can you tell us which things specifically you find comforting or calming?

Are there certain sensory inputs that you don't like or avoid?

- Certain sounds
- Certain smells
- Certain tastes
- Things I can touch (like clothing or certain textures)
- Things I see (like bright lights etc)
- Certain movements (like car rides)

Can you tell us which things specifically you avoid?

For example: loud unexpected noises

Do you know why you avoid them?

How do they make you feel?

Does your feelings about sensory input change on different days or in different places?

(e.g. does it change based on how you feel, other things that have occurred in the day, tiredness, etc.)

Please describe:

What do you usually do to cope with these feelings?

If certain things you see make you feel uncomfortable or upset, like bright lights, how do you manage this? What do you do?

If certain things you hear make you feel uncomfortable/upset, like loud unexpected noises, how do you manage this? What do you do?

If certain things you feel on your skin make you feel uncomfortable/upset, like clothing, how do you manage this? What do you do?

If certain smells make you feel uncomfortable/upset, how do you manage this? What do you do?

If certain tastes make you feel uncomfortable/upset, how do you manage this? What do you do?

If certain body movements make you feel uncomfortable, like car rides, how do you manage this? What do you do?

How do others around you help you to manage when these happen?

For example has anyone at home or school done anything to make it easier for you?

Is there anything you have tried that is unhelpful?

Is there anything other people do which is unhelpful?

Questionnaire feedback:

We are creating a questionnaire that will help us understand how people cope with different sensory inputs. We want to make sure this questionnaire makes sense to young people and includes everything it should.

Is there anything you think would be important to include in this questionnaire?

Please open this link to our Sensory modulation questionnaire. We would be grateful for any of your thoughts by answering the questions below.

Imagine you were asked to fill in this questionnaire. Is there anything that is unclear on the questionnaire?

Do the questions make sense?

Is there anything you would like to say about the way the questions are worded?

Is there anything you would like to change on this questionnaire?

Is there anything you think is missing or should be added?

For example other ways you cope with sensory input that are not already included?

Is there anything in particular you like about the questionnaire or think we should keep?

Is there anything else you would like to say about how you found the questionnaire?

Thank you for completing this survey. It may be helpful for us to talk to you more about your experiences. Please let us know below if you would be happy for us to contact you.

- Yes, you may contact me via the email address I provided
- No, please do not contact me

Appendix JJ: TDRP - Semi-structured Interview Schedule - Experts Focus Group

Chief Investigator:
Eloise Maguire, Trainee Clinical Psychologist
Oxford Institute of Clinical Psychology Training and Research
eloise.ainger@hmc.ox.ac.uk

Experts in the Field Focus group
Interview schedule
The Development of an Adolescent Sensory Coping Measure

Setting up the focus group:
Introductions and housekeeping for online forum (i.e. cameras can stay off if preferable)

Consent forms and agree confidentiality between group members. Check informed consent for audio recording. If all consent, start the audio recording.

Introduction to the focus group:
Thank you all for taking the time to attend this focus group. As you know, this study is a starting point of distinguishing between different clinical groups, ASD and developmental trauma in particular. This study is focused on developing an adolescent sensory coping measure which we will ask the general population to complete, and then validate for autistic individuals or people with traits of ASD, and individuals who have had adverse childhood experiences.

In order to develop this measure, I have consulted the literature, and discussed this with my supervisors. We have identified items that make up a tentative questionnaire, and we are hoping to develop this further with your expertise and experience. There are no right or wrong answers, and it is likely that you will have encountered very different clinical presentations and experiences, all of which are really valuable for us to hear about. It would be great to hear about different sensations, feelings and behaviours you have encounted in your clinical work with young people. After this focus group we will also consult with young people themselves about what they do to manage sensory sensations.

Introductions:
Ask everyone to just introduce themselves if they feel comfortable and say which team they are from.

Discussion:
We know that everyone will experience sensory inputs very differently in the general population, and that these fluctuate depending on several factors such as our mood, mental state and environment. As clinicians we know that sensory sensitivities are seen in a range of

different clinical presentations. We are really keen to understand how the general population experience their sensory sensitivities, how they respond to them and whether they differ across different clinical groups.

By sensory sensitivities, I mean individuals who find certain sensory inputs (sounds, smells, textures etc.) uncomfortable, either physically or emotionally.

Q1: Could you share a little about the individuals you have encountered who experience sensory sensitivities?
Prompt: What was their sensitivity, how did it impact them, how did they present?

Q2: In your experience, what strategies did these individuals use in order to cope with these difficult sensory experiences?

Q3: Please spend a couple of minutes looking over the list of coping strategies [will be displayed on the shared screen] that were revealed during the literature search. Are there any additional aspects that you have encountered in your work that are missing?
Prompt: General thoughts about this list

Q4: Please spend a couple of minutes looking over the proposed questionnaire items [will be displayed on the shared screen]. What are your thoughts on this as a measure?
Prompt: Do these make sense to you given the people you see with sensory sensitivities?
Does it capture everything it is trying to capture?
Are there key aspects missing? Is it adequate and comprehensive?
In your experience, how do you find the wording? Is it clear, respectful?
Would you suggest any adaptations to the existing measure?

Q5: In your opinion, what is important for this measure to capture for you as professionals?
Prompt: Do you think this measure will be useful in your setting? For what purpose?
What would this measure need to capture?
What would need to change for it to capture this?

Ending:
Summarise the discussion. Thank participants for their time.

Service users:
We are really keen to hear from service users on this topic too. Some of you may be aware we were recruiting for another service user focus group but am aware this may not suit a lot of young people, so we have now changed this to an online survey. Just waiting on ethics to sign this off, but if you do have any young people aged 13-18yrs who experience sensory sensitivities who might be interested, I will be sending around links shortly.

Appendix KK: TDRP - Information Sheet – Questionnaire validation (13-15yrs)

Chief Investigator:
Eloise Maguire, Trainee Clinical Psychologist
Oxford Institute of Clinical Psychology Training and Research
eloise.ainger@hmc.ox.ac.uk

The Development of an Adolescent Sensory Coping Measure for use within Non-Clinical and Clinical Presentations

QUESTIONNAIRE (13-15yrs) PARTICIPANT INFORMATION SHEET

1. Why is this research being conducted?

We all experience "sensory input" all the time. Sensory input is when our senses are being used, such as sight, hearing, smell, taste, and touch. It can also be movement and the sense of our bodies. We all experience these these things differently. For some people, sensory input (like noise and smells) are more difficult to process and manage. This can mean they might experience certain things more or less intensely than others. This can be uncomfortable for some.

At the moment, we don't have a good way of measuring how people manage sensory input. We are developing a questionnaire that will help us understand how people generally manage sensory experiences.

We spoke to young people and experts to develop items for a new questionnaire. Completing this questionnaire will help us finalise the questions We will then ask autistic individuals and individuals who have experienced difficult life experiences to complete the questionnaire. This will tell us if there are any differences in the way they manage sensory input.

2. Why have I been invited to take part?

You have been invited to take part because you are a young person between the ages of 13-18 years and are able to complete the questionnaire by yourself.

3. Do I have to take part?

No. You can ask questions about the research before deciding whether or not to take part. If you do take part, you can stop at any time by telling us. You do not have to tell us why.

4. What will happen to me if I take part in the research?

You will be asked to complete some questionnaires. These are questionnaires telling us about you, and a measure of how you cope with sensory input. There are 5 questionnaires in total. Completing this questionnaire will take around 30-40 minutes. We will ask you to complete these by yourself. You will only be asked to take part once. The questionnaires will need to be completed all together at the same time.

5. Is there anything to worry about if I take part?

As part of this study, we will ask you to tell us more about yourself. This includes asking you about any difficult or upsetting experiences you may have had. If you find this upsetting, you can stop completing the questionnaire at any time. You do not have to tell us why.

If you feel you need to speak with someone for support, please see below for details of how to do so:

- Call 111 for the 24/7 Mental Health Helpline
- Call Samaritans (116 123) any time of day for free confidential support

You may find further information and helpful tools on the following websites:

- Oxford Health CAMHS website: https://www.oxfordhealth.nhs.uk/camhs/self-care/
- YoungMinds website: https://www.youngminds.org.uk

It can be helpful to discuss how you are feeling with someone you know and trust. This may be a parent, teacher, school nurse, friend, family member, GP or other professional.

We will not ask you to tell us your name or birthday. This means no one will recognise you from the information you give.

6. Are there any benefits in taking part?

This study will not directly help you but the information you provide will help us to create a new questionnaire. We hope this can be used by professionals to help understand how different people manage their sensory experiences. This will enable them to know how to help.

7. How will we use information about you?

We will need to use information from you for this research project.

This information will include your:

- Age
- Gender
- Ethnicity
- Parent's occupation/education
- Any diagnoses related to sensory sensitivities.

We will use this information to do the research or to check your records to make sure that the research is being done properly.

We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

All information we collect will be anonymous. This means we will never ask for your name or any contact details, so you cannot be recognised. All information about you will be kept secure and private, and will only be seen by the researcher and supervisors. This information will be kept for three years.
Other research data, like your answers to the questionnaires, will be stored for 10 years. The

researcher and supervisors will have access to the research data. It may also be shared with a sponsor's representative.

8. *Where can you find out more about how your information is used?*

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- our leaflet available from https://www.oxfordhealth.nhs.uk/privacy/
- by asking or contacting one of the research team [eloise.ainger@hmc.ox.ac.uk]
- by sending an email to Oxford Health Data Protection Officer at mark.underwood@oxfordhealth.nhs.uk

9. ***What will happen if I don't want to carry on with the study?***

You can stop being part of the study at any time. You do not have to tell us why. We will not be able to delete the information about you that we already have. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

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

This study will be part of the researchers Clinical Psychology training. The results will be written up in a report and given to teachers and other students at the University. The report might also be published in a scientific magazine. You will not be personally identified in the reports. This means you can't be recognised in the reports.

11. What if something goes wrong?

If you or your parents/carers have any worries about the way you were treated during the study, please talk to Eloise Maguire, Chief Investigator, Oxford Institute of Clinical Psychology Training and Research, Isis Education Centre, Warneford Hospital, Oxford, tel: 01865 226431, email: eloise.ainger@hmc.ox.ac.uk or Dr Myra Cooper: 01865 226431, myra.cooper@ox.ac.uk

If you would like to speak to someone outside of the study about any concerns or complaints, you can do this through the Patient Advice and Liaison Service (PALS). PALS, Oxford Health

NHS Foundation Trust, PALS Office, Warneford Hospital, Warneford Lane, Oxford OX3 7JX. Tel: 0800 3287971. E-mail: PALS@oxfordhealth.nhs.uk

12. Who has reviewed this study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect participants' interests. This study has been reviewed and given favourable opinion by Hertfordshire and Cambridgeshire Research Ethics Committee (22/EE/0031). This study has been also reviewed by, and received ethics clearance through, Oxford Health Foundation Trust.

13. Further Information and Contact Details

If you would like to discuss the research with someone beforehand (or if you have questions afterwards), please contact: Eloise Maguire, Oxford Institute of Clinical Psychology Training and Research, Isis Education Centre, Warneford Hospital, Oxford.
tel: 01865 226431 email: eloise.ainger@hmc.ox.ac.uk

Appendix LL: TDRP - Information Sheet – Questionnaire validation (16-18yrs)

Chief Investigator:
Eloise Maguire, Trainee Clinical Psychologist
Oxford Institute of Clinical Psychology Training and Research
eloise.ainger@hmc.ox.ac.uk

The Development of an Adolescent Sensory Coping Measure for use within Non-Clinical and Clinical Presentations

QUESTIONNAIRE (16-18yrs) PARTICIPANT INFORMATION SHEET

1. *Why is this research being conducted?*

We all experience "sensory input" all the time. Sensory input is when our senses are being used, such as when we are looking at something, hearing a noise, smelling something, taste, and touch. It can also be movement and the sense of our bodies. We all experience these things differently. For some people, sensory input (like noise and smells) are more difficult to process and manage. For example, for some autistic individuals and some people who have had difficult things happen in their life. These individuals also share a lot of other common features. This can make it harder for professionals to diagnose correctly and help them in the most appropriate way. We think that the way they manage sensory input might be one way they differ.

At the moment, we don't have a good way of measuring how people manage sensory input as there are no questionnaires that look at this. This study therefore aims to develop a questionnaire that will help us understand how people generally manage sensory input or experiences.

Questionnaire items were developed by talking to young people who experience sensory sensitivities. We also spoke to experts and professionals. Completing this questionnaire will help us finalise the questions We will then ask autistic individuals and individuals who have

experienced difficult life experiences to complete the questionnaire, which will tell us if there are any differences in the way they manage sensory input.

2. Why have I been invited to take part?

You have been invited to take part because you are a young person between the ages of 13-18 years and are able to complete the questionnaire by yourself.

3. Do I have to take part?

No. You can ask questions about the research before deciding whether or not to take part. If you do agree to take part, you can stop at any time by telling us. You do not have to tell us why.

4. What will happen to me if I take part in the research?

You will be asked to complete some questionnaires. These are some baseline questionnaires to tell us a little bit more about you, and then a measure of how you cope with sensory input. There are 5 questionnaires in total. It is anticipated that the completion of the questionnaire will take a total of 30-40 minutes. We will ask you to complete these by yourself. You will only be asked to take part once. The questionnaires will need to be completed in a single session.

5. Are there any potential risks in taking part?

As part of this study, we will ask you to tell us more about yourself. This will include asking you about any difficult or upsetting experiences you may have had in the past. If you find this upsetting you are free to stop the questionnaire at any time without telling us why. There will be information about where you can get extra help if you need it. This will be at the beginning and end of that specific questionnaire, and at the end of all the questionnaires.
To reduce any potential risks, no personal data will be collected, to reduce the chance of you being identified.

If you feel you need to speak with someone for support, please see below for details of how to do so:

- Call 111 for the 24/7 Mental Health Helpline
- Call Samaritans (116 123) any time of day for free confidential support

You may find further information and helpful tools on the following websites:

- Oxford Health CAMHS website: https://www.oxfordhealth.nhs.uk/camhs/self-care/
- YoungMinds website: https://www.youngminds.org.uk

It can be helpful to discuss how you are feeling with someone you know and trust. This may be a parent, teacher, school nurse, friend, family member, GP or other professional.

6. Are there any benefits in taking part?

There will be no direct or personal benefit to you from taking part in this research. We hope that this study will lead to a questionnaire that can be used by different professionals to help understand how different people manage their sensory experiences.

7. How will we use information about you?

We will need to use information from you for this research project.

This information will include your:

- Age
- Gender
- Ethnicity
- Parent's occupation/education
- Any diagnoses related to sensory sensitivities.

We will use this information to do the research or to check your records to make sure that the research is being done properly.

We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

All information we collect will be anonymous, as we will never ask for your name or any contact details. All information will be stored electronically on an encrypted password protected NHS computer and secure server, One Drive. All data will only be seen by the researcher and supervisors. This information will be kept for three years and then will be destroyed. Other research data, like your answers to the questionnaires, will be stored for 10 years after the written report is published or released. The researcher and supervisors will have access to the research data. Responsible members of the sponsor's representative may be given access to data for monitoring and/or audit of the research.

8. Where can you find out more about how your information is used?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- our leaflet available from https://www.oxfordhealth.nhs.uk/privacy/
- by asking or contacting one of the research team [CI or study team email]
- by sending an email to Oxford Health Data Protection Officer at mark.underwood@oxfordhealth.nhs.uk

9. What will happen if I don't want to carry on with the study?

You can stop being part of the study at any time, without giving a reason, but we will not be able to withdraw the information about you that we already have. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

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

This study will be part of the researchers Clinical Psychology training. The results will be written up in a report and given to teachers and other students at the University. The report might also be published in a scientific magazine. You will not be personally identified in the reports.

11. What if something goes wrong?

If you have any concerns about the way you have been approached or treated during the study, please talk to, Eloise Maguire, Chief Investigator, Oxford Institute of Clinical Psychology

Training and Research, Isis Education Centre, Warneford Hospital, Oxford, tel: 01865 226431, email: eloise.ainger@hmc.ox.ac.uk or Dr Myra Cooper: 01865 226431, myra.cooper@ox.ac.uk

If you wish to speak to an independent body about any concerns or complaints about any aspect of the way you have been approached or treated during this study, you can do this through the Patient Advice and Liaison Service (PALS). PALS, Oxford Health NHS Foundation Trust, PALS Office, Warneford Hospital, Warneford Lane, Oxford OX3 7JX. Tel: 0800 3287971. E-mail: PALS@oxfordhealth.nhs.uk

12. Who has reviewed this study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect participants' interests. This study has been reviewed and given favourable opinion by Hertfordshire and Cambridgeshire Research Ethics Committee (22/EE/0031). This study has been also reviewed by, and received ethics clearance through, Oxford Health Foundation Trust.

13. Further Information and Contact Details

If you would like to discuss the research with someone beforehand (or if you have questions afterwards), please contact: Eloise Maguire, Oxford Institute of Clinical Psychology Training and Research, Isis Education Centre, Warneford Hospital, Oxford.
tel: 01865 226431 email: eloise.ainger@hmc.ox.ac.uk

Appendix MM: TDRP - Consent Form – Questionnaire validation (13-18yrs)

Chief Investigator:
Eloise Maguire, Trainee Clinical Psychologist
Oxford Institute of Clinical Psychology Training and Research
eloise.ainger@hmc.ox.ac.uk

QUESTIONNAIRE PARTICIPANT CONSENT FORM

IRAS Reference: 289550

The Development of an Adolescent Sensory Coping Measure for use within Non-Clinical and Clinical Presentations

If you would like to take part in completing the questionnaire please complete the consent form below.

Please tick each box

1	I confirm that I have read and understand the information sheet version 3 dated 15/03/2022 for the above study. I have had a chance to think about the information, ask questions and have had these answered.	☐
2	I understand that I do not have to do the questionnaire and that it is my choice. I know that I can stop at any time without telling us why. I will be taking part anonymously, and therefore I will not be able to withdraw data I have already provided. I understand that doing or not doing the questionnaire and will not affect my CAMHS support in any way.	☐
3	I understand that the data/my responses collected during the study may be looked at by other people outside the research team. For example, Eloise Maguire and staff that support Eloise Maguire. These people will never be people I know. My family, friends and teachers will not see it.	☐
4	I understand who will have access to the anonymous data provided (including age, gender, ethnicity, parental occupation, any diagnoses, any physical health difficulties such as sight/hearing difficulties), how the data/information will be stored and what will happen to the data at the end of the project.	☐
5	I agree to take part in the study	
6	*For individuals under 16 years:* My parent/guardian has agreed for me to take part in this study	☐

Researcher signature: _____ Date:

In order for you to continue anonymously, we are not able to send you a copy of your consent form. If you would like a copy, please 'print-screen' or take an image of this page before submitting. The research team will keep a copy of this form.

Appendix NN: TDRP - Social Media Advertisement – Questionnaire Validation



Appendix OO: TDRP - Demographic Survey - Questionnaire validation

Chief Investigator:
Eloise Maguire, Trainee Clinical Psychologist
Oxford Institute of Clinical Psychology Training and Research
eloise.ainger@hmc.ox.ac.uk

Before completing the survey, please provide some information about yourself:

Age (years):

How do you describe yourself?

- Male
- Female
- Non-binary / third gender
- Prefer to self-describe
- Prefer not to say

Ethnicity

- White British
- White Irish
- Other White background
- Indian
- Pakistani
- Bangladeshi
- Chinese
- Other Asian background
- African
- Caribbean
- Other Black, African or Caribbean background
- Arab

- White and Black carribbean
- White and Black African
- White and Asian
- Other mixed ethnic background
- Other

What is your parent's job?

Diagnoses (Please tick all that apply) that may impact your sensory experiences:

- Visual impairment
- Hearing impairment
- Autism Spectrum Disorder
- ADHD (Attention Deficit Hyperactivity Disorder)
- Sensory Processing Disorder
- Experienced 'trauma' or difficult life event
- Other
- I'm not sure
- Prefer not to say
- None of the above

Appendix PP: TDRP - Developed Sensory Measure for Questionnaire Validation

The Sensory Modulation Questionnaire:

Sensory input includes things you can see, hear, touch, taste, and smell. It also includes movement and the sense of your body. We all experience sensory input differently. Certain sensory inputs may feel comfortable or good and some may feel uncomfortable or bad. Different people respond to these inputs in different ways. This questionnaire asks about your level of comfort with different sensory experiences. It will then ask how you respond to these feelings. We will also ask about any sensory inputs you look for.

Please read the following statements and select the options that best describe your experience. At the end of the questions, please submit your responses.

--- page break ---

Please tell us whether you **avoid** any of the following, and why, by ticking the relevant statements below:

	✓
Certain tastes (e.g. spicy/sweet food)	
I do this because:	
It makes me feel safer	
I just don't like it	
Another reason: Please explain [open text]	
I'm not sure why	
Please add more information if you can: *[free text]*	
Certain food textures	
I do this because:	
It makes me feel safer	
I just don't like it	
Another reason: Please explain [open text]	
I'm not sure why	
Please add more information if you can: *[free text]*	
Certain smells (e.g. food smells)	
I do this because:	
It makes me feel safer	
I just don't like it	
Another reason: Please explain [open text]	
I'm not sure why	
Certain visual inputs (e.g. bright lights/colours/objects)	
I do this because:	
It makes me feel safer	
I just don't like it	
Another reason: Please explain [open text]	
I'm not sure why	
Certain things I can feel (e.g. water/sand, clothing, or other people touching me)	
I do this because:	
It makes me feel safer	
I just don't like it	
Another reason: Please explain [open text]	
I'm not sure why	
Certain noises (e.g. loud noises, or specific sounds)	
I do this because:	
It makes me feel safer	
I just don't like it	
Another reason: Please explain [open text]	
I'm not sure why	
Certain movements (e.g. using swings or slides)	
I do this because:	

It makes me feel safer	
I just don't like it	
Another reason: Please explain [open text]	
I'm not sure why	
Certain body positions or movements (e.g. stretching, banging of body parts such as rough play, clapping etc.)	
I do this because:	
It makes me feel safer	
I just don't like it	
Another reason: Please explain [open text]	
I'm not sure why	
Is there anything else you avoid? Please describe: *[open text]*	
I do this because:	
It makes me feel safer	
I just don't like it	
Another reason: Please explain [open text]	
I'm not sure why	

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Sensory input includes things you can see, hear, touch, taste, and smell. It also includes movement and the sense of your body. We all experience sensory input differently. Certain sensory inputs may feel comfortable or good and some may feel uncomfortable or bad. When sensory input makes us feel uncomfortable, unsafe or bad, we all use strategies to help us with these feelings. We all respond to these experiences and feelings in different ways.

Please tick the how frequently you use the following strategies:

		Never	Rarely	Sometimes	A lot of the time	Always
1	I cover my nose					
2	I make my own noises/sounds					
3	I move away					
4	I change position frequently					
5	I distract myself or I switch to another activity					
6	I withdraw or move away from others					
7	I move away from what is providing the sensory input					
8	I put on music or earphones to listen to music					
9	I wear sunglasses or tinted glasses outside even when it is cloudy					

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Sensory input includes things you can see, hear, touch, taste, and smell. It also includes movement and the sense of your body. We all experience sensory input differently. Certain sensory inputs may feel comfortable or good and some may feel uncomfortable or bad. When sensory input makes us feel uncomfortable, unsafe or bad, we all use strategies to help us with these feelings. We all respond to these experiences and feelings in different ways.

Please tick the how frequently you use the following strategies:

10	I cover my ears					
11	I shut down emotionally					
12	I hurt others physically					
13	I tend to look down rather than at my surroundings					
14	I wear noise cancelling headphones or earmuffs					
15	I cover my eyes					
16	I prefer doing things where I can be still**					
17	I say things that people say are rude or horrible					
18	I withdraw from activities where I have to move my body a lot (e.g. sports)					
19	I have memory blanks or ‘zone out’					

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Sensory input includes things you can see, hear, touch, taste, and smell. It also includes movement and the sense of your body. We all experience sensory input differently. Certain sensory inputs may feel comfortable or good and some may feel uncomfortable or bad. When sensory input makes us feel uncomfortable, unsafe or bad, we all use strategies to help us with these feelings. We all respond to these experiences and feelings in different ways.

Please tick the how frequently you use the following strategies:

20	I become upset or tearful					
21	*I like to explore new places					
22	I eat the same things over and over again (without trying anything new)					
23	I hurt myself (e.g. scratching, pinching, biting, banging my body against something)					
24	I touch people in a way that they tell me they don't like					
25	I look out for more things that might cause me upset (e.g. things that might make loud noises etc.)					
26	I pace around the room					
27	*I only go to places I know					
28	I ask for hugs or other deep pressure (e.g. hand holding)					
29	I touch/mouth my hair					

---- page break -----

Sensory input includes things you can see, hear, touch, taste, and smell. It also includes movement and the sense of your body. We all experience sensory input differently. Certain sensory inputs may feel comfortable or good and some may feel uncomfortable or bad. When sensory input makes us feel uncomfortable, unsafe or bad, we all use strategies to help us with these feelings. We all respond to these experiences and feelings in different ways.

Please tick the how frequently you use the following strategies:

30	I rock my body backwards and forwards or side to side					
31	I go to rooms with lots of noise in (e.g. the kitchen or bathroom rather than bedroom or living room)					
32	I wear mainly tight or heavy clothing					
33	I walk on my tiptoes					
34	I find objects with bright colours or reflections					
35	I sit on my feet or with crossed legs					
36	I want foods with lots of flavour					
37	I change the way things look by putting my hands to my eyes					
38	I often push or play roughly with others					
39	I use perfumed candles or other smells I like					

---- page break ----

Sensory input includes things you can see, hear, touch, taste, and smell. It also includes movement and the sense of your body. We all experience sensory input differently. Certain sensory inputs may feel comfortable or good and some may feel uncomfortable or bad. When sensory input makes us feel uncomfortable, unsafe or bad, we all use strategies to help us with these feelings. We all respond to these experiences and feelings in different ways.

Please tick the how frequently you use the following strategies:

40	I move my hands/fingers/arms over and over again					
41	I sit under heavy objects or blankets					
42	I purposely bang my body parts with my hands or on a hard surface					
43	I put non-food items (e.g. objects, clothes) in my mouth					
44	I make noises with my mouth or body (e.g. tapping on surfaces)					
45	I make noises with different objects (e.g. scrunching paper or banging doors)					
46	I look into the sun or bright lights					
47	I touch people so hard that they say it hurts them					
48	I hold objects with lots of pressure (e.g. gripping a pencil hard, pushing a pencil into the page when I write)					
49	I spend time really looking at other people (e.g. making eye contact)					

---- page break ----

Sensory input includes things you can see, hear, touch, taste, and smell. It also includes movement and the sense of your body. We all experience sensory input differently. Certain sensory inputs may feel comfortable or good and some may feel uncomfortable or bad. When sensory input makes us feel uncomfortable, unsafe or bad, we all use strategies to help us with these feelings. We all respond to these experiences and feelings in different ways.

Please tick the how frequently you use the following strategies:

50	I fidget in my seat and/or change positions a lot					
51	I put lotions/creams on my skin					
52	I make or find certain noises (e.g. listening to videos of certain sounds, or placing my ear on things that make noise)					
53	I tell others something isn't right by shouting/screaming					
54	I bring objects to my nose					
55	I do activities where I can move my body, like swinging on a swing, swimming**					
56	I look at objects/watch them spin close to my eyes					
57	I am always moving, even when I don't need to					
58	I jump and run a lot					
59	I move my body in the same way repetitively					

---- page break ----

Sensory input includes things you can see, hear, touch, taste, and smell. It also includes movement and the sense of your body. We all experience sensory input differently. Certain sensory inputs may feel comfortable or good and some may feel uncomfortable or bad. When sensory input makes us feel uncomfortable, unsafe or bad, we all use strategies to help us with these feelings. We all respond to these experiences and feelings in different ways.

Please tick the how frequently you use the following strategies:

60	I move quickly					
61	I stretch out my limbs/muscles and sometimes overstretch them (e.g. bending my fingers back, locking my knees)					
62	I rub or squint my eyes in the light					
63	I stroke or rub certain objects/textures					
64	I make the same noises over and over					
65	I crash into the floor or other people/objects on purpose					
66	People tell me that sometimes I get too close to them					
67	I wear short sleeves / shorts when it's cold, and long sleeves / trousers when it's hot.					
68	I spend time really looking at objects carefully					
69	I try to distract my mind on to other things					

Sensory input includes things you can see, hear, touch, taste, and smell. It also includes movement and the sense of your body. We all experience sensory input differently. Certain sensory inputs may feel comfortable or good and some may feel uncomfortable or bad. We all respond to these experiences and feelings in different ways. When sensory input makes us feel uncomfortable, unsafe or bad, we all use strategies to help us with these feelings. We all respond to these experiences and feelings in different ways.

Please tick the how frequently you use the following strategies:

70	I prefer to be in busy places with lots of people					
71	I will place myself in colder areas without wearing warm clothing					
72	I will place myself in hotter areas					
73	I use other sensory inputs to cover another one up (e.g. different smells, drink water)					
74	I stay with people who make me feel comfortable/safe					
75	I try to tolerate the feeling					
76	Other: [please describe things you or others may have noticed] [*open text*]					

Some people may harm themselves or others when they are distressed. If this is something you do, it can be really helpful to talk to someone you know and trust about how you are feeling. This might be a parent, teacher, friend or professional. The Young Minds (https://www.youngminds.org.uk) and the Oxford Health website (https://www.oxfordhealth.nhs.uk/camhs/self-care/self-harm/) also have more information about things that may help.

Thank you for completing this questionnaire. Please submit your responses.

Appendix QQ: TDRP - Autism Quotient – Adolescent

APPENDIX 1: The Adolescent AQ

	Definitely agree	Slightly agree	Slightly disagree	Definitely disagree
1. S/he prefers to do things with others rather than on her/his own.				
2. S/he prefers to do things the same way over and over again.				
3. If s/he tries to imagine something, s/he finds it very easy to create a picture in her/his mind.				
4. S/he frequently gets so strongly absorbed in one thing that s/he loses sight of other things.				
5. S/he often notices small sounds when others do not.				
6. S/he usually notices car number plates or similar strings of information.				
7. Other people frequently tell her/him that what s/he has said is impolite, even though s/he thinks it is polite.				
8. When s/he is reading a story, s/he can easily imagine what the characters might look like.				
9. S/he is fascinated by dates.				
10. In a social group, s/he can easily keep track of several different people's conversations.				
11. S/he finds social situations easy.				
12. S/he tends to notice details that others do not.				
13. S/he would rather go to a library than a party.				
14. S/he finds making up stories easy.				
15. S/he finds her/himself drawn more strongly to people than to things.				
16. S/he tends to have very strong interests, which s/he gets upset about if s/he can't pursue.				
17. S/he enjoys social chit-chat.				
18. When s/he talks, it isn't always easy for others to get a word in edgeways.				
19. S/he is fascinated by numbers.				
20. When s/he is reading a story, s/he finds it difficult to work out the characters' intentions.				
21. S/he doesn't particularly enjoy reading fiction.				
22. S/he finds it hard to make new friends.				
23. S/he notices patterns in things all the time.				
24. S/he would rather go to the theatre than a museum.				
25. It does not upset him/her if his/her daily routine is disturbed.				
26. S/he frequently finds that s/he doesn't know how to keep a conversation going.				
27. S/he finds it easy to "read between the lines" when someone is talking to her/him.				
28. S/he usually concentrates more on the whole picture, rather than the small details.				
29. S/he is not very good at remembering phone numbers.				
30. S/he doesn't usually notice small changes in a situation, or a person's appearance.				
31. S/he knows how to tell if someone listening to him/her is getting bored.				
32. S/he finds it easy to do more than one thing at once.				
33. When s/he talks on the phone, s/he is not sure when it's her/his turn to speak.				
34. S/he enjoys doing things spontaneously.				
35. S/he is often the last to understand the point of a joke.				
36. S/he finds it easy to work out what someone is thinking or feeling just by looking at their face.				

Appendix 1. (Continued)

	Definitely agree	Slightly agree	Slightly disagree	Definitely disagree
37. If there is an interruption, s/he can switch back to what s/he was doing very quickly.				
38. S/he is good at social chit-chat.				
39. People often tell her/him that s/he keeps going on and on about the same thing.				
40. When s/he was younger, s/he used to enjoy playing games involving pretending with other children.				
41. S/he likes to collect information about categories of things (e.g. types of car, types of bird, types of train, types of plant, etc.).				
42. S/he finds it difficult to imagine what it would be like to be someone else.				
43. S/he likes to plan any activities s/he participates in carefully.				
44. S/he enjoys social occasions.				
45. S/he finds it difficult to work out people's intentions.				
46. New situations make him/her anxious.				
47. S/he enjoys meeting new people.				
48. S/he is a good diplomat.				
49. S/he is not very good at remembering people's date of birth.				
50. S/he finds it very to easy to play games with children that involve pretending.				

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An AQ-Adol score >30 was used to define the ‘autism’ group in examining H_5. This is the clinical cut-off suggested by Baron-Cohen et al. (2006) as approximately 90% of autistic individuals, and 0% of controls scored above this when validating the measure.

Appendix RR: TDRP - Email confirmation to adapt the AQ-Adol

From: Joanna Davis <jd695@medschl.cam.ac.uk>
Sent: 16 June 2020 13:10
To: Stacey James (RNU)
Subject: FW: AQ-adolescent

Dear Dr Stacey

Thank you for your email, the ARC have not validated a self-report version of the AQ adolescent test. Please feel free to adapt it for your needs, however we would ask that you acknowledge the original as the source and also understand that it wouldn't be suitable for use with individuals with intellectual disability. If you need any further information or clarification you can email our Director of Research Strategy, Carrie Allison, her email address is
cla29@cam.ac.uk.

Best wishes
Jo

Joanna Davis
Autism Research Centre Administrator / Admin Team Leader
Autism Research Centre
Department of Psychiatry
University of Cambridge
Douglas House
18B Trumpington Road
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01223 465215
www.autismresearchcentre.com
To support autism research: www.justgiving.com/autismresearchtrust

From: Stacey James (RNU)
Sent: 09 June 2020 17:02
To: Autism Research Centre <support@autismresearchcentre.com>
Subject: AQ-adolescent

Hi there,

I'm wondering whether ARC have developed/investigated a self-report version of the adolescent AQ. I am part of a small research group in oxford who are hoping to use a self-report screening measure of ASD as part of a study looking at sensory modulation in a number of clinical groups, including ASD.

Would be great to discuss with someone in the team if possible.

Many thanks,

Dr. James Stacey

Appendix SS: TDRP - CYW ACE-Q Teen Self Report

CYW Adverse Childhood Experiences Questionnaire (ACE-Q) Teen Self-Report

To be completed by Patient

Today's Date: _____

Your Name: _____ Date of birth: _____

Many children experience stressful life events that can affect their health and development. The results from this questionnaire will assist your doctor in assessing your health and determining guidance. Please read the statements below. Count the number of statements that apply to you and write the total number in the box provided.

Please DO NOT mark or indicate which specific statements apply to you.

1) Of the statements in section 1, HOW MANY apply to you? Write the total number in the box. ☐

Section 1. *At any point since you were born...*

- Your parents or guardians were separated or divorced
- You lived with a household member who served time in jail or prison
- You lived with a household member who was depressed, mentally ill or attempted suicide
- You saw or heard household members hurt or threaten to hurt each other
- A household member swore at, insulted, humiliated, or put you down in a way that scared you OR a household member acted in a way that made you afraid that you might be physically hurt
- Someone touched your private parts or asked you to touch their private parts in a sexual way that was unwanted, against your will, or made you feel uncomfortable
- More than once, you went without food, clothing, a place to live, or had no one to protect you
- Someone pushed, grabbed, slapped or threw something at you OR you were hit so hard that you were injured or had marks
- You lived with someone who had a problem with drinking or using drugs
- You often felt unsupported, unloved and/or unprotected

2) Of the statements in section 2, HOW MANY apply to you? Write the total number in the box. ☐

Section 2. *At any point since you were born...*

- You have been in foster care
- You have experienced harassment or bullying at school
- You have lived with a parent or guardian who died
- You have been separated from your primary caregiver through deportation or immigration
- You have had a serious medical procedure or life threatening illness
- You have often seen or heard violence in the neighborhood or in your school neighborhood
- You have been detained, arrested or incarcerated
- You have often been treated badly because of race, sexual orientation, place of birth, disability or religion
- You have experienced verbal or physical abuse or threats from a romantic partner (i.e. boyfriend or girlfriend)

CYW ACE-Q Teen SR (13-19 yo) © Center for Youth Wellness 2015

This measure was chosen based on the breadth of adversities included and accessibility of the measure (i.e. number of items and training requirements). Although other measures were also suitable (e.g. Childhood Trust Events Survey (Cincinnati Childrens, 2017); Elsie Allen Health Center ACE survey (Paull, 2015); Yale-Vermonth Adversity in Childhood Scale (Holbrook et al., 2014)) (see Lee et al., 2018), the ACE-Q did not require respondents to specify which ACE/s they had experienced. This was important as this element could cause participants' unnecessary distress. The ACE-Q also includes community-based stressors which were deemed to be more representative of a broad and diverse adolescent population (Cronholm et al., 2015).

An ACE-Q score of >4 was used to define the 'ACE' group to examine H_5. This cut-off is recommended within the user guide as being clinically relevant. This is in line with the validated adult measure, as a score >4 is associated with long-term health consequences (Felitti et al., 1998; Hughes et al., 2017).

Appendix TT: TDRP - Sensory Processing Scale Inventory

Date _____ Name _____
Pre Treatment _____
Post Treatment _____

Checklist #1 [check each description that applies to you]

These garments bother me

1 ☐ seams in clothing
2 ☐ tags in clothing
3 ☐ socks
4 ☐ changing from long to short pants
5 ☐ accessories (e.g., watch, jewelry, scarf, hats)
6 ☐ elastic on clothing
a ☐ restrictive/confining clothing (suits, button down shirts, tie or scarf)
7 ☐ fuzzy or furry textured clothes (e.g., sweaters, collars, etc.)
8 ☐ wool clothes

These aspects of self care bother me

9 ☐ washing or wiping face
10 ☐ cutting toenails or fingernails
b ☐ wearing hair down around face or neck
11 ☐ having haircut or hair clipped
12 ☐ hair washing or drying
13 ☐ hair brushing or combing
14 ☐ getting dressed
15 ☐ brushing teeth
16 ☐ getting dirty
18 ☐ having messy hands
19 ☐ having a messy mouth

These tactile sensations bother me

20 ☐ mud
21 ☐ lotion or sunblock
22 ☐ shaving cream
24 ☐ foods
25 ☐ hair care products (greasy/sticky)
26 ☐ kissing
27 ☐ coarse carpet
28 ☐ light stroking touch

These visual sensations bother me

29 ☐ brightly colored or patterned materials (e.g. clothes, upholstery, drapes, wallpaper)
c ☐ movement of people/vehicles (in the street, at the mall, or restaurant)
d ☐ viewing events while in a large audience
30 ☐ fluorescent lights
31 ☐ fast moving images in the movies or TV
32 ☐ visually cluttered environments
33 ☐ busy pictures in books or complex and busy images in artwork

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Date _____ Name _____
Pre Treatment _____
Post Treatment _____

These smells bother me

34 ☐ perfume/cologne
35 ☐ cleaners/disinfectants
36 ☐ bath products
37 ☐ soaps
38 ☐ air fresheners

These aspects of food and eating bother me

39 ☐ salty foods (e.g., nuts or chips)
40 ☐ soft foods
41 ☐ lumpy foods
42 ☐ slimy foods
43 ☐ soup with vegetables or meat pieces
44 ☐ spicy foods (e.g., spicy dip, hot sauce)
45 ☐ eating bread crust
e ☐ feeling full after a meal
46 ☐ food preparation/cooking
47 ☐ new/unfamiliar foods

These sounds bother me

48 ☐ sound of utensils against each other (e.g., spoon in bowl, knife on plate)
49 ☐ clothing that makes noise (e.g., swishing cloth, accessories)
50 ☐ door bell ringing
51 ☐ dog barking
52 ☐ sirens
53 ☐ alarms
54 ☐ radio or TV in the background
55 ☐ fluorescent lights
56 ☐ someone talking when I am trying to concentrate
57 ☐ clock ticking
f ☐ multiple conversations occurring simultaneously
58 ☐ construction or landscaping equipment
59 ☐ water running or dripping in the background

Sounds in these places bother me

60 ☐ toilet flushing in the bathroom
61 ☐ appliances/small motor noises (e.g., blender, vacuum, hair dryer, electric shaver) at home
62 ☐ concerts
63 ☐ large gatherings
64 ☐ restaurants
g ☐ busy streets
65 ☐ parades
66 ☐ malls
67 ☐ gymnasium

These aspects related to movement bother me

68 ☐ climbing activities
69 ☐ walking or climbing up open stairs
70 ☐ experiencing heights
71 ☐ walking or standing on moving surfaces
72 ☐ Being lifted off of the ground (e.g. ski lift, ferris wheel)
74 ☐ going on amusement park rides
75 ☐ going up or down escalators
76 ☐ chewing foods

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Date_____
Pre Treatment_____
Post Treatment _____

Name_____

Checklist #2 [check each description that applies to you]

Typically I have a less intense response than others to:

1 ☐ vaccines
2 ☐ bruises or cuts
3 ☐ hurting myself
4 ☐ being touched on the arm or back (ex. unaware)
5 ☐ dirt on myself
6 ☐ objects that are too hot or too cold to touch
7 ☐ bumping into things or falling over objects

Typically I do not notice:

8 ☐ food or liquid left on lips
9 ☐ hands or face that are messy/dirty
10 ☐ drooling or food that has fallen out of my mouth
11 ☐ the need to use the toilet
12 ☐ feelings of hunger (ie.g. not seeking food when hungry)
13 ☐ over-filling mouth when eating
a ☐ feeling cold
14 ☐ feelings of being "full"
15 ☐ strong or noxious odors

Typically I do not notice:

16 ☐ activity within a busy environment
17 ☐ an object coming toward my eyes quickly
18 ☐ someone entering or leaving the room
19 ☐ materials or people in the room needed to complete an activity

Typically I do not respond:

20 ☐ when my name is called or or I have to be touched to pay attention (hearing is OK)
21 ☐ when a new sound is introduced
22 ☐ to unexpected loud sounds (e.g. fire drills, hall bells or other loud noises)
23 ☐ when given directions or instructions only once
24 ☐ to a normal volume speaking voice (e.g.. others speak loudly to gain my attention)

I:

25 ☐ perform movements in a slow and plodding fashion
26 ☐ seem to have little reaction to movement activities (e.g. swinging, amusement park rides, climbing, trampoline)
27 ☐ often feel like I am in my own world or 'tuned out'
28 ☐ do not visually scan the environment (look around)
29 ☐ leave clothing twisted on my body

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Date _____ Name_____
Pre Treatment _____
Post Treatment _____

Checklist #3 [check each description that applies to you]

I have a constant desire for:

1 ☐ swinging
2 ☐ being upside down
3 ☐ jumping and crashing (e.g. beds or other surfaces)
4 ☐ bumping, pushing or hitting other people
5 ☐ fidgeting, wiggling and restlessness which interferes with daily routines (ex. Can't sit still, fidgets)
6 ☐ twirling/spinning throughout the day (e.g.. likeing dizzy feeling or don't get dizzy)
7 ☐ movement in chair during class, at a meal, or a business meeting
8 ☐ deliberately falling when running or playing sports
9 ☐ movement without regard to safety (e.g. engaging in extreme sports to an excess)
10 ☐ bumping or pushing body against objects/walls
11 ☐ flapping or clapping hands, biting self or other repetitive actions
12 ☐ changing from one activity to another so that it interferes with completion of activities
13 ☐ pushing, pulling and hanging off things (e.g. refrigerator doors, cabinets, partner or friend's hands)

I have a constant desire for:

14 ☐ looking at spinning objects (e.g. ceiling fans, toys with wheels, floor fans)
15 ☐ watching fast changing TV or movie segments
16 ☐ watching flickering or blinking lights
17 ☐ watching visually stimulating scenarios (ex. rock concert, nightclubs, Times Square, Las Vegas)
18 ☐ staring at people or objects

I have a constant desire for:

19 ☐ touching people to the point of irritating others (I get in others' personal space)
20 ☐ being overly affectionate with others
21 ☐ feeling vibrations (e.g.. stereo speakers, washer, dryer)
22 ☐ touching/feeling objects
23 ☐ being held
24 ☐ banging head, biting hands, pinching , scratching or pulling hair
25 ☐ splashing excessively during baths or in the pool

I have a constant desire for:

26 ☐ licking, sucking, or chewing on non-food items e.g. hair, pencils, clothing
27 ☐ eating crunchy, chewy or hard foods to the exclusion of other textures
28 ☐ putting things in mouth
29 ☐ excessive kissing

I have a constant desire to :

30 ☐ eat foods with strong flavors/tastes (e.g. bitter, sour, spicy)
a ☐ drink beverages with strong flavors
31 ☐ smell people/pets
32 ☐ deliberately smell or taste objects during other activities

I have a constant desire to:

33 ☐ talk and have difficulty taking turns
34 ☐ speak in a loud voice
35 ☐ make a lot of noises during activities
36 ☐ increase the volume on the TV , CD or radio
37 ☐ make strange sounds

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Date _____ Name_____
Pre Treatment _____
Post Treatment _____

Checklist #4 [check each description that applies to you]

I do not:

1 ☐ have a preferred hand for writing, cutting, etc.
2 ☐ hold paper with other hand while cutting or writing
3 ☐ reach across my body to grab objects

I do not have adequate strength so I:

4 ☐ have difficulty turning knobs or handles that require some pressure
5 ☐ have a loose grasp on objects i.e. pen, pencil, knife, cell phone or things that I am carrying
6 ☐ have a rather tight, tense grasp on objects but cannot sustain
7 ☐ can't lift heavy objects
8 ☐ seem weaker than others my age
9 ☐ hold a pencil/pen or other objects differently from most people

I have difficulty in these activities:

10 ☐ balancing when a bus, car or subway stops quickly
11 ☐ balancing during motor activities (ex. Biking, karate, gymnastics, etc.)
12 ☐ keeping good desk posture (slumping, leaning, head close to computer, propping head on hand)
13 ☐ turning head alone (I turn my whole body to look at something/someone)
14 ☐ tiring easily, especially when standing or holding particular body position
15 ☐ catching myself when falling

I:

16 ☐ am a weak hugger or hand shaker
17 ☐ keep my mouth open most of the time
18 ☐ tire easily
19 ☐ sit partly on and off the chair
20 ☐ have 'loose' or 'floppy' feeling muscles
21 ☐ use one hand or the other but avoid using my hands together
22 ☐ avoid or need encouragement for any heavy work (ex. pushing, pulling, lifting weights)

I have difficulty coordinating 2 sides of body to:

23 ☐ clap rhythmically to my favorite songs
24 ☐ engagning in sports (e.g. Skiing, jogging, running)
25 ☐ jump with both feet together
26 ☐ ride a bicycle

I have difficulty with the following visual activities:

27 ☐ keeping track of place on page (e.g. Reading)
28 ☐ following a moving object with eyes
a ☐ moving eyes between far and near (e.g.copying from whiteboard during a meeting

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Date _____ Name_____
Pre Treatment _____
Post Treatment _____

Checklist #5 [check each description that applies to you]

I have difficulty in these language activities:

1 ☐ hard to understand when I speak (speech/articulation problems)
2 ☐ unable to follow two or three step directions

I have difficulty with these motor activities:

3 ☐ tasks that have several steps
4 ☐ learning exercise steps or routines (e.g. Aerobics, Zumba, Yoga, Treadmill, Elliptical etc)
5 ☐ learning new motor tasks (e.g. sports: skiing, tennis, golf, etc.)
6 ☐ following the steps of a recipe
7 ☐ maintaining or copying rhythms
8 ☐ balancing
10 ☐ walking on bumpy/uneven ground (e.g. hiking an uneven trail)
11 ☐ playing sports
12 ☐ driving
13 ☐ riding a bike (pedaling or pushing with feet and steering)
15 ☐ catching something that is thrown to me

I:

16 ☐ am clumsy or seem not to know how to move my body, bump into things
17 ☐ prefer sedentary (quiet) activities to movement activities
18 ☐ approach new motor activities in an overly cautious manner
19 ☐ get lost easily (even in familiar places)
20 ☐ am accident prone
21 ☐ talk myself through tasks
22 ☐ use inefficient ways of doing things (ex. wasting time, moving slowly, do things the hardest way)
23 ☐ tend to break objects when having problems using them
24 ☐ have difficulty formulating goals (ideas) for action

I have difficulty with these fine motor activities:

25 ☐ handling small manipulative objects (ex. paperclips, safety pin, thumbtacks, screws/nails)
26 ☐ blowing (e.g. whistling)
27 ☐ wrapping a present
28 ☐ snapping fingers
29 ☐ operating a manual can opener
30 ☐ putting a belt through all belt loops
31 ☐ grasping a pencil or pen
a ☐ texting on a cell phone
32 ☐ applying paste to toothbrush

I have difficulty with these work activities:

33 ☐ drawing or copying
34 ☐ cutting with scissors
35 ☐ staying between the lines when writing
36 ☐ poor handwriting
b ☐ filling in forms

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Date _____
Pre Treatment _____
Post Treatment _____

Name_____

I have difficulty with these daily living tasks:

37 ☐ licking an ice cream cone
38 ☐ using a spoon or cup
39 ☐ handling eating utensils
40 ☐ putting clothing off or on
41 ☐ placing arm or leg correctly in clothing
42 ☐ tying shoes
43 ☐ fasteners (ex. buttons, zipper, snaps, buckles)
44 ☐ putting on pierced earrings and/or a necklace
45 ☐ putting on a watch

I:

46 ☐ eat in a messy sloppy manner
47 ☐ eat or dress slowly
48 ☐ put clothes on backwards or inside out
49 ☐ look disheveled

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Date_____
Pre Treatment_____
Post Treatment_____

Name _____

Checklist #6 [check each description that applies to you]

I have trouble finding:

1 ☐ utensils on the table or in the sink
2 ☐ desired item in drawer or on shelf
3 ☐ desired garment in closet or shirt in drawer
4 ☐ socks that match
5 ☐ objects in distracting backgrounds (e.g. shoes in messy room, utensil in 'junk drawer')
6 ☐ printed figures that appear similar (e.g.' b' and 'd/p', or '+' and 'x')
7 ☐ a familiar face in a crowd
8 ☐ the appropriate aisle in a store
9 ☐ taking notes from a screen
10 ☐ things that are moving from those that are not moving
11 ☐ objects without touching and feeling them rather than looking at them

I have trouble judging:

12 ☐ the amount of force needed for a task (ex. Pushing grocery cart, kicking a ball)
13 ☐ appropriate pressure with pencil, pen, markers (w/o breaking or flattening)
14 ☐ timing and distance (difficulty catching, batting a ball or throwing to a target)
15 ☐ if I am moving or if things around me are moving
16 ☐ where food is within the mouth (ex. I don't chew fully before swallowing or I bite my cheek or lip when eating)

I have trouble distinguishing (without looking):

17 ☐ objects in pocket, purse or drawer by feel
18 ☐ what is in my hands
19 ☐ what is touching me
20 ☐ buttons and button holes

I have trouble distinguishing:

21 ☐ the location of sounds
22 ☐ what is said
23 ☐ the words to a song when listening on a radio
24 ☐ specific sounds that are similar (ex. caT vs. caP or bacK or baT)
25 ☐ the taste of different foods

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Appendix UU: TDRP - Confirmation of sponsorship

Oxford Health
NHS Foundation Trust

Natalia Jastrzębska
Research Manager
Research and Development Department
Warneford Hospital
Warneford Lane
Oxford
OX3 7JX
Email: research@oxfordhealth.nhs.uk

21/12/2021

Confirmation of Sponsorship

Re: The development of an adolescent sensory coping measure for use within non-clinical and clinical presentations
Research and Development Reference: 15675

Dear Eloise Maguire,

On behalf of Oxford Health NHS Foundation Trust, I am pleased to confirm Oxford Health NHS Foundation Trust will act as a sponsor for the above research as outlined in the application received.

Protocol Version 1 dated 17.11.2021 is recognised as the most current to date.

Conditions of Approval
The following conditions apply to this approval:

a) The study sponsorship is confirmed subject to formal approval from HRA and any other relevant approving body.
b) Should you plan to leave your position in OHFT, you will notify R&D immediately of your plans, to enable discussions around the future of study conduct.
c) The Trust expects the named Principal Investigator to allocate regular support time to the study; this must be agreed with the research team prior to the study commencing. This may be reviewed by R&D at any time.
d) All relevant documents will be maintained and will be sent to research@oxfordhealth.nhs.uk, to facilitate compliance checks, formal audits and regulatory inspections.
e) You will notify R&D via the email above of any amendments.
f) You will promptly inform R&D via the email above of the end of the study.

I wish you every success with the study.

Yours sincerely,

Natalia Jastrzębska
Research Manager

Appendix VV: TDRP - HRA Ethics approval letter

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Mrs Eloise Maguire
Trainee Clinical Psychologist
Oxford Health NHS Foundation Trust
Isis Education Centre
Warneford Hospital
Headington, Oxford
OX3 7JX

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

17 March 2022

Dear Mrs Maguire,

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**The development of an adolescent sensory coping measure for use within non-clinical and clinical presentations**
IRAS project ID:	**289550**
Protocol number:	**PID15675**
REC reference:	**22/EE/0031**
Sponsor	**Oxford Health NHS Foundation Trust**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

Appendix WW: TDRP - Sponsorship approval for non-substantial amendment

Dear Mrs Maguire,

IRAS Project ID:	289550
Short Study Title:	The Development of an Adolescent Sensory Coping Measure
Amendment No./Sponsor Ref:	NSA 01
Amendment Date:	24 June 2022
Amendment Type:	Non Substantial Non-CTIMP

I am pleased to confirm **HRA and HCRW Approval** for the above referenced amendment.

You should implement this amendment at NHS organisations in England and Wales, in line with the guidance in the amendment tool.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/.

Please contact amendments@hra.nhs.uk for any queries relating to the assessment of this amendment.

Kind regards

Sarah Prothero
Approvals Specialist
Health Research Authority
Ground Floor | Skipton House | 80 London Road | London | SE1 6LH
E.amendments@hra.nhs.uk
W. www.hra.nhs.uk

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Appendix XX: TDRP - HRA approval for Substantial Amendment 1

NHS
Health Research Authority

East of England - Cambridgeshire and Hertfordshire Research Ethics Committee

Equinox House
City link
Nottingham
NG2 4LA

05 September 2022

Mrs Eloise Maguire
Isis Education Centre
Warneford Hospital
Oxford
OX3 7JX

Dear Mrs Maguire,

Study title:	**The development of an adolescent sensory coping measure for use within non-clinical and clinical presentations**
REC reference:	**22/EE/0031**
Protocol number:	**PID15675**
Amendment number:	**Substantial Amendment 1**
Amendment date:	**12 August 2022**
IRAS project ID:	**289550**

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Completed Amendment Tool [Amendment Tool]	1	12 August 2022
Copies of materials calling attention of potential participants to the research [Community sample advert]	2	
Participant consent form [YP Consultation Consent Form (13-15yrs)]	4	28 July 2022
Participant consent form [YP Consultation Consent Form (16-18yrs)]	4	28 July 2022
Participant consent form [YP Consultation Consent Form (parent)]	4	28 July 2022
Participant information sheet (PIS) [YP Consultation Information sheet (13-15yrs)]	4	18 July 2022
Participant information sheet (PIS) [YP Consultation Information Sheet (16-18yrs)]	5	18 July 2022

Appendix YY: TDRP - HRA approval for Substantial Amendment 2

Health Research Authority

East of England - Cambridgeshire and Hertfordshire Research Ethics Committee

Equinox House
City link
Nottingham
NG2 4LA

Tel: 0207 104 8019

Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.

07 November 2022

Mrs Eloise Maguire
Isis Education Centre
Warneford Hospital
Oxford
OX3 7JX

Dear Mrs Maguire

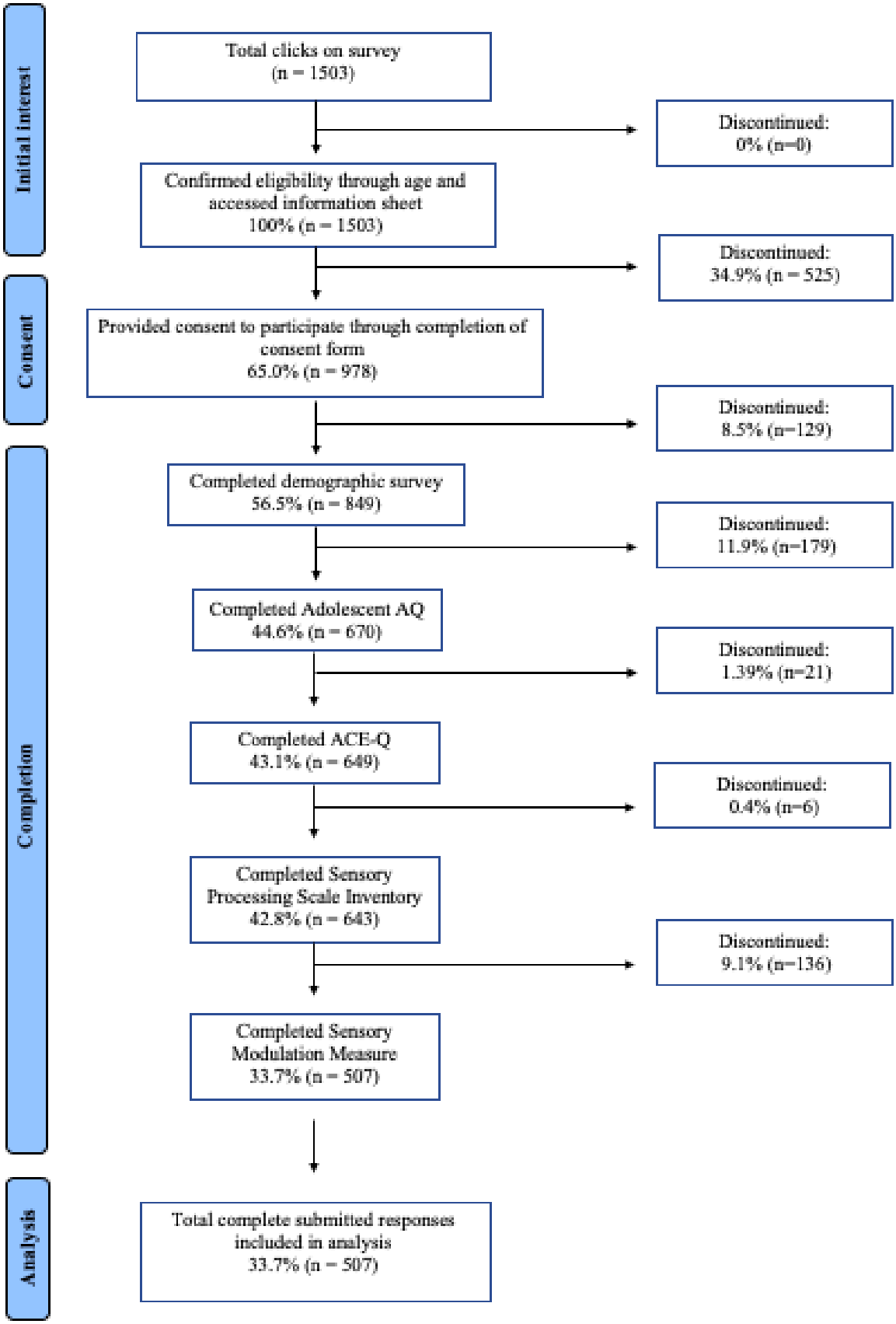
Study title:	**The development of an adolescent sensory coping measure for use within non-clinical and clinical presentations**
REC reference:	**22/EE/0031**
Protocol number:	**PID15675**
Amendment number:	**SA 002**
Amendment date:	**24 October 2022**
IRAS project ID:	**289550**

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Appendix ZZ: TDRP - Data cleaning of online responses



Appendix AAA: TDRP - Rotated Factor Loadings for all Items in the Sensory Modulation Measure.

Item	Withdrawal	Sensory seeking	Inter-personal
I tend to look down rather than at my surroundings	**0.77**	-0.15	-0.10
I prefer to be in busy places with lots of people	**-0.76**	**0.47**	0.17
I cover my ears	**0.73**	-0.10	-0.09
I withdraw or move away from others	**0.72**	-0.16	-0.15
I withdraw from activities where I have to move my body a lot (e.g. sports)	**0.70**	-0.39	0.10
I shut down emotionally	**0.65**	-0.02	0.03
I move away from what is providing the sensory input	**0.62**	-0.14	-0.10
I look out for more things that might cause me upset (e.g. things that might make loud noises etc.)	**0.58**	-0.02	-0.03
I make the same noises over and over	**0.58**	0.06	0.20
I rock my body backwards and forwards or side to side	**0.57**	0.20	-0.00
I only go to places I know	**0.56**	-0.27	0.16
I prefer doing things where I can be still	**0.55**	**-0.43**	0.11
I cover my eyes	**0.54**	0.04	0.09
I walk on my tiptoes	**0.54**	0.05	-0.03
I move my body in the same way repetitively	**0.53**	0.35	-0.10
I stroke or rub certain objects/textures	**0.52**	0.18	0.02
I move my hands/fingers/arms over and over again	**0.50**	0.37	-0.17
I wear noise cancelling headphones or earmuffs	**0.50**	-0.02	-0.06
I eat the same things over and over again (without trying anything new)	**0.49**	-0.16	0.19
I hurt myself (e.g. scratching, pinching, biting, banging my body against something)	**0.48**	0.20	-0.01
I have memory blanks or ‘zone out’	**0.48**	0.21	-0.02
I become upset or tearful	**0.47**	-0.07	0.13
I make my own noises/sounds	**0.47**	0.13	0.15
I rub or squint my eyes in the light	**0.44**	0.18	0.06
I purposely bang my body parts with my hands or on a hard surface	**0.42**	0.24	0.06
I make noises with my mouth or body (e.g. tapping on surfaces)	**0.41**	0.31	0.03
I make or find certain noises (e.g. listening to videos of certain sounds, or placing my ear on things that make noise)	**0.41**	0.19	0.20
I pace around the room			
I spend time really looking at objects carefully	0.39	0.30	0.03
I put lotions/creams on my skin	-0.39	0.30	0.11
I try to distract my mind on to other things	0.38	0.17	-0.01
I sit on my feet or with crossed legs		0.35	0.25
I put non-food items (e.g. objects, clothes) in my mouth	0.35	0.16	0.22
I stay with people who make me feel comfortable/safe	0.35	0.05	-0.01
I hold objects with lots of pressure (e.g. gripping a pencil hard, pushing a pencil into the page when I write)	0.34	0.22	0.11

I use other sensory inputs to cover another one up (e.g. different smells, drink water)	0.33	0.16	0.22
I sit under heavy objects or blankets	0.32	0.12	0.18
I change the way things look by putting my hands to my eyes	0.31	0.23	0.22
I cover my nose	0.30	0.11	-0.06
I wear sunglasses or tinted glasses outside even when it is cloudy	0.28	0.03	0.13
I put on music or earphones to listen to music	0.27	0.06	0.03
I touch/mouth my hair	0.26	0.21	0.14
I wear short sleeves / shorts when it's cold, and long sleeves / trousers when it's hot.	0.22	0.17	0.13
I am always moving, even when I don't need to	0.14	**0.67**	-0.14
I jump and run a lot	-0.09	**0.67**	-0.04
I move quickly	0.01	**0.64**	-0.07
I do activities where I can move my body, like swinging on a swing, swimming	-0.13	**0.64**	0.03
I like to explore new places	**-0.44**	**0.60**	-0.05
I fidget in my seat and/or change positions a lot	**0.41**	**0.44**	-0.21
I look into the sun or bright lights	0.00	**0.43**	0.1-
I go to rooms with lots of noise in (e.g. the kitchen or bathroom rather than bedroom or living room)	-0.34	**0.41**	0.13
I look at objects/watch them spin close to my eyes	0.18	**0.40**	0.16
I stretch out my limbs/muscles and sometimes overstretch them (e.g. bending my fingers back, locking my knees)	0.21	0.39	-0.02
I find objects with bright colours or reflections	0.07	0.37	0.13
I want foods with lots of flavour	-0.24	0.34	0.14
I make noises with different objects (e.g. scrunching paper or banging doors)	0.20	0.33	0.21
I bring objects to my nose	0.19	0.32	0.08
I use perfumed candles or other smells I like	-0.12	0.28	0.16
I distract myself or I switch to another activity	0.19	0.22	0.06
I will place myself in colder areas without wearing warm clothing	0.10	0.21	0.16
I try to tolerate the feeling	0.04	0.17	-0.04
Other	0.08	0.15	0.00
I touch people in a way that they tell me they don't like	-0.06	-0.15	**0.80**
I touch people so hard that they say it hurts them	-0.11	-0.01	**0.73**
People tell me that sometimes I get too close to them	0.01	-0.01	**0.73**
I hurt others physically	0.03	-0.06	**0.60**
I often push or play roughly with others	-0.12	0.25	**0.60**
I crash into the floor or other people/objects on purpose	0.08	0.18	**0.49**
I say things that people say are rude or horrible	0.28	-0.08	**0.47**
I tell others something isn't right by shouting/screaming	0.13	0.05	**0.47**
I ask for hugs or other deep pressure (e.g. hand holding)	0.15	-0.05	0.36
I spend time really looking at other people (e.g. making eye contact)	-0.29	0.23	0.33
I wear mainly tight or heavy clothing	-0.05	0.12	0.23

I will place myself in hotter areas	-0.02	0.13	0.18
% of variance	*24.35%*	*4.59%*	*2.23%*
α	*.85*	*.76*	*.86*

Factor loadings >.4 are in bold

Appendix BBB: TDRP: The Adolescent Sensory Modulation Measure

The Sensory Modulation Questionnaire:

Sensory input includes things you can see, hear, touch, taste, and smell. It also includes movement and the sense of your body. We all experience sensory input differently. Certain sensory inputs may feel comfortable or good and some may feel uncomfortable or bad. Different people respond to these inputs in different ways. This questionnaire asks about your level of comfort with different sensory experiences. It will then ask how you respond to these feelings. We will also ask about any sensory inputs you look for.

Please read the following statements and select the options that best describe your experience. At the end of the questions, please submit your responses.

--- page break ---

Please tick the how frequently you use the following strategies:

		Never	Rarely	Sometimes	A lot of the time	Always
1	I tend to look down rather than at my surroundings					
2	I cover my ears					
3	I withdraw or move away from others					
4	I withdraw from activities where I have to move my body a lot (e.g. sports)					
5	I shut down emotionally					
6	I move away from what is providing the sensory input					
7	I look out for more things that might cause me upset (e.g. things that might make loud noises etc.)					
8	I make the same noises over and over					
9	I rock my body backwards and forwards or side to side					
10	I only go to places I know					

--page break –

Sensory input includes things you can see, hear, touch, taste, and smell. It also includes movement and the sense of your body. We all experience sensory input differently. Certain sensory inputs may feel comfortable or good and some may feel uncomfortable or bad. When sensory input makes us feel uncomfortable, unsafe or bad, we all use strategies to help us with these feelings. We all respond to these experiences and feelings in different ways.

Please tick the how frequently you use the following strategies:

11	I am always moving, even when I don't need to					
12	I jump and run a lot					
13	I move quickly					
14	I do activities where I can move my body, like swinging on a swing, swimming					
15	I look into the sun or bright lights					
16	I go to rooms with lots of noise in (e.g. the kitchen or bathroom rather than bedroom or living room)					
17	I look at objects/watch them spin close to my eyes					

---- page break -----

Sensory input includes things you can see, hear, touch, taste, and smell. It also includes movement and the sense of your body. We all experience sensory input differently. Certain sensory inputs may feel comfortable or good and some may feel uncomfortable or bad. When sensory input makes us feel uncomfortable, unsafe or bad, we all use strategies to help us with these feelings. We all respond to these experiences and feelings in different ways.

Please tick the how frequently you use the following strategies:

18	I touch people in a way that they tell me they don't like					
19	I touch people so hard that they say it hurts them					
20	People tell me that sometimes I get too close to them					
21	I hurt others physically					
22	I often push or play roughly with others					
23	I crash into the floor or other people/objects on purpose					
24	I say things that people say are rude or horrible					
25	I tell others something isn't right by shouting/screaming					

---- page break -----

Some people may harm themselves or others when they are distressed. If this is something you do, it can be really helpful to talk to someone you know and trust about how you are feeling. This might be a parent, teacher, friend or professional. The Young Minds (https://www.youngminds.org.uk) and the Oxford Health website (https://www.oxfordhealth.nhs.uk/camhs/self-care/self-harm/) also have more information about things that may help.

Thank you for completing this questionnaire. Please submit your responses.

Appendix CCC: TDRP - Additional analyses

Hypothesis: Positive correlations will be found between all sensory modulation subscales, autism scores and ACE scores.

Spearman's rho correlations were calculated, and positive low-to-moderate correlations (Cohen, 1988) were found between all sensory modulation subscales, Adolescent AQ scores, and ACE-Q scores. Although weak correlations were found between sensory-seeking and AQ/ACE scores, moderate correlations were found between both withdrawal and interpersonal subscales against the two measures (see table 7).

Table 7:

Correlation Coefficients for Sensory Modulation Subscales, Adolescent-AQ Total Scores and ACE-Q Total Scores

Variable	AQ-Adolescent	ACE-Q	Withdrawal	Sensory-seeking	Interpersonal
AQ-Adolescent	-	r_2=.25*	r_2=.62*	r_2=.15*	r_2=.32*
ACE-Q		-	r_2=.39*	r_2=.19*	r_2=.30*
Withdrawal			-	r_2=.34*	r_2=.47*
Sensory-seeking				-	r_2=.54*
Interpersonal					-

**p<.001*

H_5: Significant group differences will be found within sensory modulation subscale scores

A one-way ANOVA was performed to explore differences in sensory modulation subscale scores between groups, defined by Adolescent-AQ and ACE scores using the measures clinical cut-offs (see appendix X). Groups were similar in their demographics (see table 10)

There was a significant difference in withdrawal (*Welch's F*(3, 209.50)=75.936, *p*<.001), sensory-seeking *(Welch's F(*3, 213.243)=5.858, *p*<.001) and interpersonal *(F(*3, 227.331)=20.262, *p*<.001) subscales across the four groups. In all three subscales, scores were highest in the autism and trauma group, and lowest in the control group (see table 11).

Table 11:

Group means and standard deviations (M(SD))

Variable	Autism	Trauma	Both	Control
Withdrawal	23.87(6.39)	21.25(6.65)	28.81(5.78)	16.74(8.09)
Sensory-seeking	11.80(5.10)	12.12(5.16)	13.13(4.69)	10.46(5.62)
Interpersonal	8.23(6.01)	8.72(6.38)	10.80(6.59)	5.24(5.34)

Post-hoc comparisons using the Games-Howell procedure revealed significant differences between all groups within the withdrawal subscale; and all except the autism group and trauma group significantly differed across the interpersonal subscale. Conversely, only the autism and trauma group and control group significantly differed on the withdrawal subscale (see table 12).

Table 12:

Summary of Post-Hoc Results

Variable		*Autism vs trauma*	*Autism vs both*	*Trauma vs both*	*Autism vs Control*	*Trauma vs control*	*Both vs control*
Withdrawal	*Mean difference*	2.61*	-4.94**	-7.56**	7.13**	4.52**	12.07**
	SE	.94	.80	.74	1.10	1.05	.93
Sensory-seeking	*Mean difference*	-.33	-1.34	-1.01	1.34	1.67	2.68**
	SE	.74	.64	.58	.81	.76	.67
Interpersonal	*Mean difference*	-.49	-2.57*	-2.08*	2.99*	3.48**	5.56**
	SE	.89	.80	.75	.86	.82	.71

**p=<.05*
***p=<.001*

Appendix DDD: Journal Author Guidelines

frontiers | Frontiers in Psychology

Author guidelines

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All names are listed together and separated by commas. Provide exact and correct author names as these will be indexed in official archives. Affiliations should be keyed to the author's name with superscript numbers and be listed as follows:

- Laboratory, Institute, Department, Organization, City, State abbreviation (only for United States, Canada, and Australia), and Country (without detailed address information such as city zip codes or street names).

Example: Max Maximus1 1 Department of Excellence, International University of Science, New York, NY, United States.

Correspondence

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Example: John Smith and Barbara Smith on behalf of The Collaborative Working Group.

Abstract

As a primary goal, the abstract should make the general significance and conceptual advance of the work clearly accessible to a broad readership. The abstract should be no longer than a single paragraph and should be structured, for example, according to the IMRAD format. For the specific structure of the abstract, authors should follow the requirements of the article type or journal to which they're submitting. Minimize the use of abbreviations and do not cite references, figures or tables. For clinical trial articles, please include the unique identifier and the URL of the publicly-accessible website on which the trial is registered.

Keywords

All article types require a minimum of five and a maximum of eight keywords.

Text

The entire document should be single-spaced and must contain page and line numbers in order to facilitate the review process. The manuscript should be written using either Word or LaTeX. See above for templates.

Nomenclature

The use of abbreviations should be kept to a minimum. Non-standard abbreviations should be avoided unless they appear at least four times, and must be defined upon first use in the main text. Consider also giving a list of non-standard abbreviations at the end, immediately before the acknowledgments.

Equations should be inserted in editable format from the equation editor.

Italicize gene symbols and use the approved gene nomenclature where it is available. For human genes, please refer to the HUGO Gene Nomenclature Committee (HGNC). New symbols for human genes should be submitted to the HGNC here. Common alternative gene aliases may also be reported, but should not be used alone in place of the HGNC symbol. Nomenclature committees for other species are listed here. Protein products are not italicized.

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Chemical compounds and biomolecules should be referred to using systematic nomenclature, preferably using the recommendations by the International Union of Pure and Applied Chemistry (IUPAC).

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Life Science Identifiers (LSIDs) for ZOOBANK registered names or nomenclatural acts should be listed in the manuscript before the keywords. An LSID is represented as a uniform resource name (URN) with the following format: urn:lsid:<Authority>:<Namespace>:<ObjectID>[:<Version>]

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Acknowledgments

This is a short text to acknowledge the contributions of specific colleagues, institutions, or agencies that aided the efforts of the authors. Should the content of the manuscript have previously appeared online, such as in a thesis or preprint, this should be mentioned here, in addition to listing the source within the reference list.

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Example statement on: Markram K and Markram H (2010) The Intense World Theory – a unifying theory of the neurobiology of autism. Front. Hum. Neurosci. 4:224. doi: 10.3389/fnhum.2010.00224

Autism spectrum disorders are a group of neurodevelopmental disorders that affect up to 1 in 100 individuals. People with autism display an array of symptoms encompassing emotional processing, sociability, perception and memory, and present as uniquely as the individual. No theory has suggested a single underlying neuropathology to account for these diverse symptoms. The Intense World Theory, proposed here, describes a unifying pathology producing the wide spectrum of manifestations observed in autists. This theory focuses on the neocortex, fundamental for higher cognitive functions, and the limbic system, key for processing emotions and social signals. Drawing on discoveries in animal models and neuroimaging studies in individuals with autism, we propose how a combination of genetics, toxin exposure and/or environmental stress could produce hyper-reactivity and hyper-plasticity in the microcircuits involved with perception, attention, memory and emotionality. These hyper-functioning circuits will eventually come to dominate their neighbors, leading to hyper-sensitivity to incoming stimuli, over-specialization in tasks and a hyper-preference syndrome. We make the case that this theory of enhanced brain function in autism explains many of the varied past results and resolves conflicting findings and views and makes some testable experimental predictions.

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Reference examples

Article in a print journal Sondheimer, N., and Lindquist, S. (2000). Rnq1: an epigenetic modifier of protein function in yeast. Mol. Cell. 5, 163-172.

Article in an online journal Tahimic, C.G.T., Wang, Y., Bikle, D.D. (2013). Anabolic effects of IGF-1 signaling on the skeleton. Front. Endocrinol. 4:6. doi: 10.3389/fendo.2013.00006

Article or chapter in a book Sorenson, P. W., and Caprio, J. C. (1998). "Chemoreception," in The Physiology of Fishes, ed. D. H. Evans (Boca Raton, FL: CRC Press), 375-405.

Book Cowan, W. M., Jessell, T. M., and Zipursky, S. L. (1997). Molecular and Cellular Approaches to Neural Development. New York: Oxford University Press.

Abstract Hendricks, J., Applebaum, R., and Kunkel, S. (2010). A world apart? Bridging the gap between theory and applied social gerontology. Gerontologist 50, 284-293. Abstract retrieved from Abstracts in Social Gerontology database. (Accession No. 50360869)

Website World Health Organization. (2018). E. coli. https://www.who.int/news-room/fact-sheets/detail/e-coli [Accessed March 15, 2018].

Patent Marshall, S. P. (2000). Method and apparatus for eye tracking and monitoring pupil dilation to evaluate cognitive activity. U.S. Patent No 6,090,051. Washington, DC: U.S. Patent and Trademark Office.

Data Perdiguero P, Venturas M, Cervera MT, Gil L, Collada C. Data from: Massive sequencing of Ulms minor's transcriptome provides new molecular tools for a genus under the constant threat of Dutch elm disease. Dryad Digital Repository. (2015) http://dx.doi.org/10.5061/dryad.ps837

Theses and dissertations Smith, J. (2008) Post-structuralist discourse relative to phenomological pursuits in the deconstructivist arena. [dissertation/master's thesis]. [Chicago (IL)]: University of Chicago

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Reference examples

Article in a print journal Sondheimer N, Lindquist S. Rnq1: an epigenetic modifier of protein function in yeast. Mol Cell (2000) 5:163-72.

Article in an online journal Tahimic CGT, Wang Y, Bikle DD. Anabolic effects of IGF-1 signaling on the skeleton. Front Endocrinol (2013) 4:6. doi: 10.3389/fendo.2013.00006

Article or chapter in a book Sorenson PW, Caprio JC. "Chemoreception". In: Evans DH, editor. The Physiology of Fishes. Boca Raton, FL: CRC Press (1998). p. 375-405.

Book Cowan WM, Jessell TM, Zipursky SL. Molecular and Cellular Approaches to Neural Development. New York: Oxford University Press (1997). 345 p.

Abstract Christensen S, Oppacher F. An analysis of Koza's computational effort statistic for genetic programming. In: Foster JA, editor. Genetic Programming. EuroGP 2002: Proceedings of the 5th European Conference on Genetic Programming; 2002 Apr 3–5; Kinsdale, Ireland. Berlin: Springer (2002). p. 182–91.

Website World Health Organization. E. coli (2018). https://www.who.int/news-room/fact-sheets/detail/e-coli [Accessed March 15, 2018].

Patent Pagedas AC, inventor; Ancel Surgical R&D Inc., assignee. Flexible Endoscopic Grasping and Cutting Device and Positioning Tool Assembly. United States patent US 20020103498 (2002).

Data Perdiguero P, Venturas M, Cervera MT, Gil L, Collada C. Data from: Massive sequencing of Ulms minor's transcriptome provides new molecular tools for a genus under the constant threat of Dutch elm disease. Dryad Digital Repository. (2015) http://dx.doi.org/10.5061/dryad.ps837

Theses and dissertations
Smith, J. (2008) Post-structuralist discourse relative to phenomological pursuits in the deconstructivist arena. [dissertation/master's thesis]. [Chicago (IL)]: University of Chicago

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