**Thesis submitted in partial fulfilment of the degree of Doctor of Clinical Psychology (DClinPsych)**

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I would like to acknowledge the valuable time and contributions from the participants, service users, expert by experience, and clinicians without whom this research would not have been possible. My deepest thanks also go to my research tutors who have nurtured my professional growth with a compassion and wisdom to which I aspire to in my own practice.

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## Word Counts

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Service Improvement Project (SIP): 5000

Theory-Driven (Main) Research Project (TDRP): 5616

Executive Summary: 827

Connecting Narrative: 999

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*Note: The Service Improvement Project contained no figures.*

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# Abstracts

## A Systematic Review of the Literature: The Nature of Sleep Health and Neurocognitive Functioning in Children and Adolescents Post Traumatic Brain Injury

Disrupted sleep health is common post traumatic brain injury (TBI) in adult populations. Sleep disturbances have also been shown to impair cognition across a range of domains. Sleep health disturbances are also reported in child and adolescent post TBI, however, the association with cognition are poorly characterised in comparison to their adult counterparts. A systematic search was completed through EMBASE, PsycINFO, MEDLINE, AMED and SCOPUS for articles published between 2002-2025 pertaining to sleep and neurocognition in child and adolescent TBI populations; eighteen studies met the inclusion criteria. 2903 participants ($n$ = 2062 TBI; $n$ = 824 Controls) were included in a narrative synthesis aimed at characterising sleep health and neurocognitive functioning in children and adolescents, post TBI. Results from the synthesis are concordant with previous literature within paediatric TBI and in adult literature which suggests sleep wake disturbance is common in child and adolescent TBI populations. The results also expand on previous findings and suggest the most common form of sleep wake disturbances in children and adolescents with TBI are difficulties with initiating/maintaining sleep, excessive somnolence, and difficulties with sleep-wake transitions. Importantly, results from the synthesis indicate that TBI *in conjunction* with sleep wake disturbance negatively impacts on speed of processing and memory, and elevates attentional and executive functioning concerns, beyond TBI sequalae alone. These results are in accordance with adult literature which have indicated post TBI cognitive changes across memory, processing speed, attention and executive functioning. The results suggest there could be value in screening for sleep disturbance in child and adolescent populations with TBI, and for providing psychoeducation for families and educators to support associated neurocognitive deficits likely to be present in this population. Future research investigating proposed mechanisms for post-TBI sleep and neurocognitive difficulties would be of value in disentangling if there is a casual directional relationship.

**Service Improvement Project: Proportion and Experience of Autistic Service Users within an Outpatient Pelvic Pain Service**

Compared to the general public, autistic individuals have a higher incidence of comorbid physical health problems and psychological difficulties. Important disparities also exist in terms of access to, and experience of, healthcare. Autistic service users often report poorer healthcare accessibility and engagement.

An audit of autism prevalence was conducted with the John Radcliffe, Pelvic Pain Service (PPS), an outpatient service supporting both the physical and psychological health needs of women with pelvic pain. The aim of the audit was to identify the proportion of autistic service users accessing the PPS between December 2020-December 2022.

Semi-structured interviews were also carried out with $N = 5$ female, autistic PPS service users (identified through the audit), to explore their experience of key aspects of the PPS including the materials/methods of information communication, initial multidisciplinary assessment and group sessions offered.

The audit revealed the PPS has a larger proportion of autistic service users than there are in the general population. Thematic analysis of the interviews revealed key themes around power, communication style, expectations and practical arrangements which impacted service users' accessibility, experience and engagement with the PPS. These findings led to recommendations, supported by the PPS, to develop video walk throughs of key aspects of the service, ensuring communication style is direct, and reflects respect, compassion and non-judgment and which promotes service users' sense of agency and control, create suggested engagement guidelines for group sessions, and to consider options for offering service users alternative places to wait for appointments to reduce sensory overload.

**Key Words:** *Autistic, Pelvic Pain, Thematic Analysis, Healthcare, Service Improvement*

**Theory Driven Research Project: The Impact of Teachers' Awareness of Pupil Autism Diagnosis on Teacher Attribution, Intervention Choice and Expected Behavioural Management Efficacy when working with Restricted and Repetitive Behaviours**

**Background**: Restrictive and Repetitive Behaviours (RRB) are a diagnostic feature of autism that can obstruct inclusive practice in school classrooms. RRB can be subdivided into lower order, motor or sensory seeking mannerisms, and higher order, complex and cognitively mediated behaviours such as rituals or preference for routine. Little is known about how teachers' understanding of RRB and their management are shaped by factors such as diagnostic awareness.

**Methods**: This study used an online vignette-based design with 192 primary school teachers, randomly assigned to one of four groups which differed in autism diagnostic awareness and RRB subtype. Teachers selected a management strategy and rated attributional beliefs (locus, controllability, stability) and expected behavioural management (BM) efficacy.

**Results**: Teachers' aware of the autism diagnosis rated RRB as more internally driven, stable, and amenable to effective intervention. Higher order RRB were rated as more controllable and were associated with greater BM efficacy expectations, but only when participants were aware of the autism diagnosis. Collaborative interventions were preferred for higher order RRB regardless of diagnostic awareness, whereas for lower order RRB a collaborative intervention selection was more likely when participants were aware of the autism diagnosis. Teaching experience, diagnostic awareness, and attribution of controllability significantly predicted BM efficacy ratings.

**Conclusions**: Findings suggest autism diagnostic disclosure shapes teachers' attributions of children's agency in RRB, choice of management strategy, and their perceived BM efficacy. It could be helpful for clinicians to share with parents of autistic children the positive impact diagnostic disclosure could have on facilitating inclusive engagement in the classroom.

**Systematic Review of the Literature**
**The Nature of Sleep Health and Neurocognitive Functioning in Children and Adolescents Post Traumatic Brain Injury**

Word count: 4825

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## Abstract

Disrupted sleep health is common post traumatic brain injury (TBI) in adult populations. Sleep disturbances have also been shown to impair cognition across a range of domains. Sleep health disturbances are also reported in child and adolescent post TBI, however, the association with cognition are poorly characterised in comparison to their adult counterparts. A systematic search was completed through EMBASE, PsycINFO, MEDLINE, AMED and SCOPUS for articles published between 2002-2025 pertaining to sleep and neurocognition in child and adolescent TBI populations; eighteen studies met the inclusion criteria. 2903 participants ($n$ = 2062 TBI; $n$ = 824 Controls) were included in a narrative synthesis aimed at characterising sleep health and neurocognitive functioning in children and adolescents, post TBI. Results from the synthesis are concordant with previous literature within paediatric TBI and in adult literature which suggests sleep wake disturbance is common in child and adolescent TBI populations. The results also expand on previous findings and suggest the most common form of sleep wake disturbances in children and adolescents with TBI are difficulties with initiating/maintaining sleep, excessive somnolence, and difficulties with sleep-wake transitions. Importantly, results from the synthesis indicate that TBI *in conjunction* with sleep wake disturbance negatively impacts on speed of processing and memory, and elevates attentional and executive functioning concerns, beyond TBI sequalae alone. These results are in accordance with adult literature which have indicated post TBI cognitive changes across memory, processing speed, attention and executive functioning. The results suggest there could be value in screening for sleep disturbance in child and adolescent populations with TBI, and for providing psychoeducation for families and educators to support associated neurocognitive deficits likely to be present in this population. Future research investigating proposed mechanisms for post-TBI sleep and neurocognitive difficulties would be of value in disentangling if there is a casual directional relationship.



**Key Words**: *Sleep Health, Paediatric, Child, Adolescent, Traumatic Brain Injury (TBI), Executive Functioning, Memory, Neurocognitive Functioning*

## Background

Sleep health can be defined as a:

" … *multidimensional pattern of sleep-wakefulness, adapted to individual, social, and environmental demands, that promotes physical and mental well-being." (Buysse, 2014, p. 12).*

Disrupted sleep health is common post traumatic brain injury (TBI), across TBI severity (Mosti et al., 2016), with a prevalence ranging from 23-84% (Albrecht & Wickwire, 2020; Ayalon et al., 2007; Barshikar & Bell, 2017; Grima et al., 2016; Orff et al., 2009; Wickwire et al., 2018). Sleep disorders, such as insomnia and hypersomnia, as well as other forms of sleep-wake disturbance (SWD), such as shorter sleep duration and greater wake after sleep onset, are commonly reported in adult TBI populations a (Aoun et al., 2019; Grima et al., 2016; Mathias & Alvaro, 2012)

Sleep disorders and SWD (in the absence of TBI), in adults, impact on a range of cognitive functions such as memory, attention, speed of processing speed, visuospatial processing and executive functioning (Devore et al., 2016; Olaithe et al., 2018; Stranks & Crowe, 2016). Insomnias reportedly impact on working memory, episodic memory and some aspects of executive functioning (Fortier-Brochu et al., 2012). SWD in the form of sub-optimal sleep quantity reportedly impacting on attention and memory function (Olaithe et al., 2018).

Unsurprisingly, therefore, SWD post TBI is also associated with cognitive functioning changes, in adults, across a range of domains, including verbal and visual memory, processing speed, attention and executive functioning (Bloomfield et al., 2010; Duclos et al., 2015; Theadom et al., 2015; Wiseman-Hakes et al., 2013).

It has been proposed that cognitive functions such as attention, memory and executive functioning are particularly susceptible to synergistic interplay between sleep dysfunction and TBI sequalae (Sanchez et al., 2022; Thomas, 2021). Proposed mechanisms are multifaceted and include: chronic inflammatory processes leading to disrupted memory consolidation, aberrant production of neurotransmitters responsible for wakefulness and attention, such as orexin (Weinhold et al., 2014), and axon shearing and white matter microstructural changes in tracts integral to the memory and attentional systems (Thomas, 2021). Indeed, in keeping with this, sleep wake cycles disruption (SWCD) has been shown to predict memory function in adults with TBI (Nakase-Richardson et al., 2013).

Disturbances to sleep health, such as SWD, are also reported in children and adolescents with TBI (Botchway et al., 2019; Botchway et al., 2020; Gagner et al., 2015; Wickwire et al., 2018; Wilkinson et al., 2018; Williams et al., 2022). Given that sleep is integral for brain development (Stores & Wiggs, 2001) and healing after injury (Siegel, 2003; Stores & Wiggs, 2001), children with TBI related sleep health disruption are therefore at risk of significant deficits neurodevelopmentally and cognitively (Muzur et al., 2002).

A recent systematic review of paediatric populations post-TBI revealed a SWD prevalence rate of 20% and reported a negative correlation between SWD and cognitive, behavioural, and quality of life outcomes (Luther et al., 2020). Few studies were included that assessed aspects of cognition specifically, as this was not the primary focus of the review. Sleep health disturbances, such SWD and links with cognition remain poorly characterised in comparison to their adult counterparts as they have not been evaluated systemically (Luther et al., 2020) A systematic review and narrative synthesis was therefore conducted to characterise sleep health and neurocognitive difficulties in children and adolescents, post TBI.

**Research Questions**

1) What is the nature of sleep problems experienced by children and adolescents post TBI?
2) What is the nature of subjective neurocognitive complaints within children and adolescent populations post TBI?
3) What is the nature of objective neurocognitive difficulties experienced by children and adolescents post TBI?
4) What is the nature of the associations between sleep and neurocognitive problems in children and adolescent populations post TBI?

## Method

The study protocol developed and passed by the Doctorate in Clinical Psychology Project Approval Session panel (January 2022), was adhered to (see Appendix A).

A proportion (30%) of all articles were independently reviewed by a second researcher (EK) at each stage of the review, in accordance with the course and PRISMA

guidelines to reduce the risk of bias. Acceptable inter-rater agreement was deemed if criteria of $K > .81$ was met (Altman, 1990)

## Eligibility Criteria

Studies were included that involved children and adolescents (aged between 3-25 years old) with a TBI, where there was assessment of both sleep problems and cognition. These were limited to full-text, peer-reviewed articles published in English. See Table 1 for inclusion criteria. A broad range of study designs (e.g., single case designs, case report/series, cross-sectional, and longitudinal designs) were deemed suitable for inclusion to maximise the available data.

Table 1 Inclusion Criteria, Definition and Justification

| Criterion | Definition |
|---|---|
| Participants with a Traumatic Brain Injury (TBI) | TBI is defined as:<br>*" an acquired disruption of the normal function or structure of the brain caused by a head impact or external force."*<br><br>*TBI is classified as mild, moderate, or severe. The term 'concussion' can be used interchangeably with mild TBI."*<br><br>As defined by the BMJ Best Practice (Haydel, 2024, *para,* 1 and *para*. 6) |
| Children and Adolescent Population | Participants between 3-25 years of age.<br><br>The youngest age for inclusion was 3 years of age, as this is the age at which key aspects of cognition such as executive functioning (Gioia et al., 2000) and memory (Kemp & Korkman, 2010) be assessed using neuropsychological assessment.<br><br>The oldest age for inclusion was 25 years, as this is the approximate age at which neurocognitive development is considered to be complete (Arain et al., 2013). |
| Sleep Health/Disturbance Assessed | Administration of objective measures of sleep such as actigraphy or polysomnography and subjective measures of sleep such as self-report or parent-report questionnaires pertaining to aspects of sleep health/SWD. |
| Cognition Assessed | Administration of age-appropriate objective measures of cognitive performance such as neuropsychological assessment and subjective |

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|---|---|
| | measures of cognition or cognitive concerns such as parent-report questionnaires assessing cognitive concerns. |
| Peer-Reviewed | Published in a scientific journal (defined as "journals" by Oxford university Bodleian libraries). |

Given that the purpose of the review was to synthesise data on sleep health disturbance, as a result of TBI, and related cognitive deficits, where there was mention of participants having a pre-morbid confounds such as neurodevelopmental disorders (Ballester et al., 2020; Carmassi et al., 2019; Cohen et al., 2014) or chronic health conditions (Evans et al., 2017; Long et al., 2008) these studies were excluded from the review. See Table 2 for Exclusion criteria. Potential post-TBI confounds including mood disturbance and pain (Baglioni et al., 2010) were also tabulated and considered in the review.

Table 2 Exclusion Criteria, Definition and Justification

| Criterion | Definition |
|---|---|
| Pre-morbid sleep-wake disorder (1) | Sleep-wake disorder, which pre-dates the TBI, defined as: *"Sleep-wake disorders encompass 10 disorders or disorder groups: insomnia disorder, hypersomnolence disorder, narcolepsy, breathing-related sleep disorders, circadian rhythm sleep-wake disorders, non-rapid eye movement (NREM) sleep arousal disorders, nightmare disorder, rapid eye movement (REM) sleep behavior disorder, restless legs syndrome, and substance/medication-induced sleep disorder. Individuals with these disorders typically present with sleep-wake complaints of dissatisfaction regarding the quality, timing, and amount of sleep. Resulting daytime distress and impairment are core features shared by all of these sleep-wake disorders."* (DSM-5, *p*. 361)<br><br>Pre-existing sleep-wake disorder could confound the results. |
| Pre-morbid neurodevelopmental disorder<br><br>(2) | Developmental disorder, which predates TBI, defined as: *"Developmental disorders are a group of conditions with onset in the developmental period. The disorders typically manifest early in development, often before the child enters grade school, and are characterized by developmental deficits that* |

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|---|---|
| | *produce impairments of personal, social, academic, or occupational functioning."*<br>(DSM-5, 2013, *p.*31)<br><br>Neurodevelopmental disorders have been shown to impact on sleep (Ballester et al., 2020; Carmassi et al., 2019; Cohen et al., 2014) which could therefore confound the results. |
| Pre-morbid chronic health condition<br>(3) | Chronic Health condition, which redates TBI, defined as<br>*"health problem that requires ongoing management over a period of years or decades and is one that cannot currently be cured but can be controlled with the user of medication and/or therapies."*<br>(NHS Data Model and Dictionary, NHS England 2024, *para.*2)<br><br>Chronic health problems can impact on sleep (Evans et al., 2017; Long et al., 2008) which could therefore confound the results. |
| Consideration of sleep and cognition in the context<br><br>of TBI was not the primary focus<br><br>(4) | Where sleep and cognition are not mentioned in the aims of the article. |

**Measures of effect of sleep on neurocognitive problems**

Given the heterogeneous nature of designs and associated analyses to be included in the review, a variety of outcomes were extracted and synthesised.

For group comparisons, an effect was recorded and synthesised when authors reported a statistically significant difference between groups (using appropriate parametric or non-parametric test) at a threshold of $p < .05$ (Altman, 1990).

For regression/correlational analyses effects were recorded and synthesised when authors reported regression coefficients at statistically significant threshold of $p < .05$ (Altman, 1990), with at least a small effect size $r = .2$ (Götz et al., 2022).

Prevalence of SWD or cognitive deficit was reported when authors included reference to measure specific clinical threshold (i.e., *T*-score).

A key list of appropriate objective and subjective measures to assess cognition within the age range stipulated was developed with the advice of Paediatric Clinical Neuropsychologist, see Appendix B.

A key list of appropriate objective and subjective measures to assess sleep within the age range stipulated was developed with the advice of Clinical Psychologist specialising in the field of behavioural sleep medicine, see Appendix C.

**Search Strategy**

The systematic search was conducted by the first author using the following electronic databases: Ovid MEDLINE® Epub Ahead of Print, In-Process & Other Non-Indexed Citations; AMED (Allied and Complimentary Medicine) 1985-present (Ovid); Embase 1974 to present (Ovid), PsycINFO 1806 to present (Ovid), AMED Allied and Complimentary Medicine 1985- present (Ovid); PsycINFO 1806 to present and SCOPUS. This was completed with guidance provided by a librarian at the Bodleian Libraries, Oxford. The initial search was completed in May 2022 with a subsequent, updated search completed in August 2025.

Four sets of search terms (pertaining to TBI, child and adolescent populations, sleep, and cognition) were included alongside adjacency, proximity and Boolean operators, field tags and field restrictions to facilitate a return of articles which would meet the aims of the search. This was completed with guidance provided by a librarian at the Bodleian Libraries, Oxford. See Appendix D for full search Strategy.

**Selection of Studies**

The selection process involved elimination of duplicate studies and elimination of texts which were not full-texts, such as conference abstracts or brief reports. Screening of titles and abstracts for eligibility was completed in totality by one researcher. 30% of the titles and abstracts were independently reviewed by a second reviewer (EK) to reduce risk of bias. Inter-rater reliability was calculated to be $K = 0.94$, 97% agreement. Discrepancies were discussed and consensus achieved subsequently.

The full texts were the reviewed for eligibility in totality by one researcher. 30% of the full articles were reviewed by EK. Inter-rater reliability was calculated to be $K = 0.86$, 95% agreement. Discrepancies were discussed and consensus achieved subsequently.

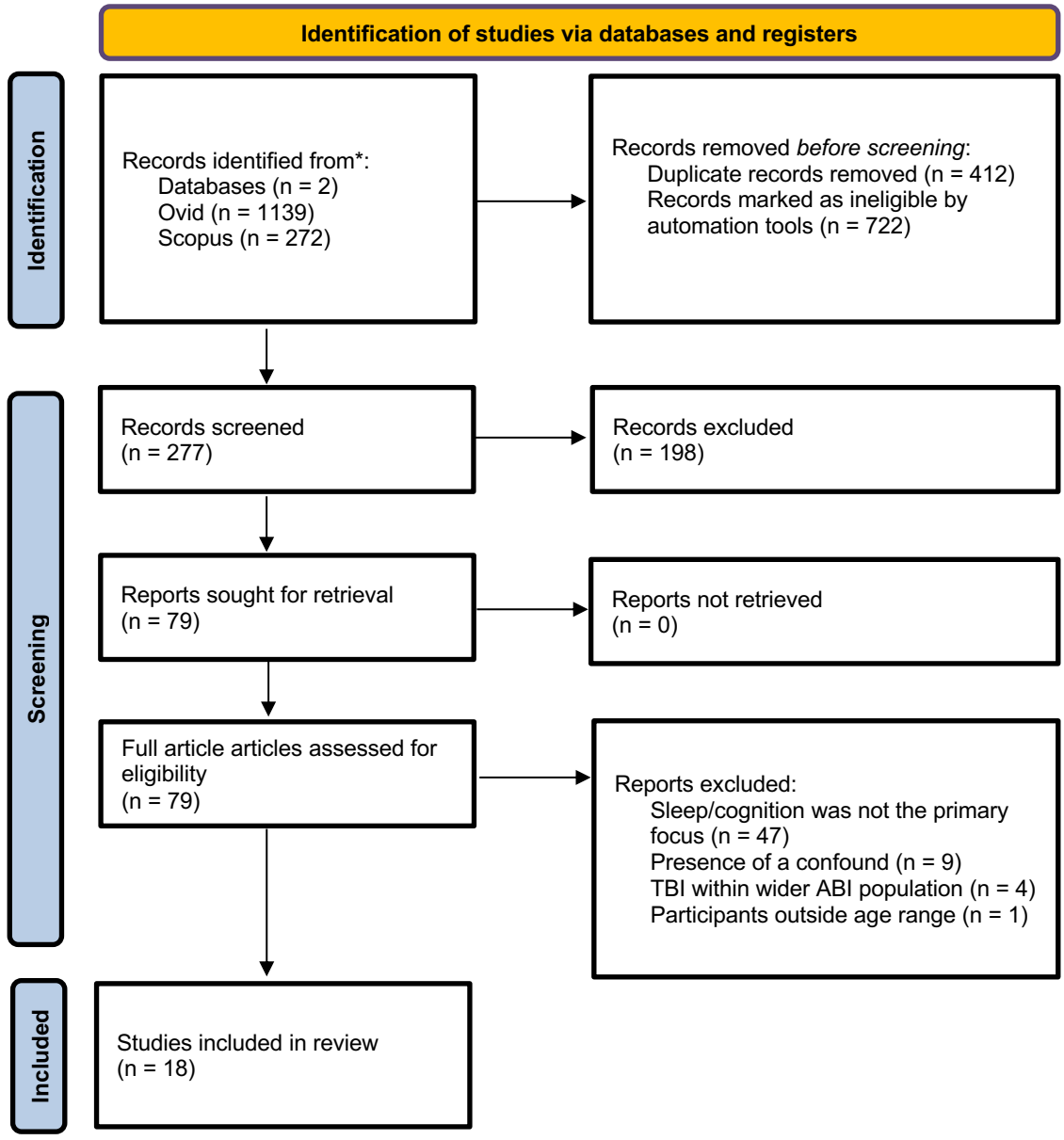


*Figure 1 - Flow Diagram of Study Selection Process in accordance with PRISMA (Haddaway et al., 2022)*

## Data Extraction

Data were systematically extracted using an Excel data extraction table designed for this review using definitions defined in Table 1. Key characteristics of the research extracted included: authors, year of publication, country of origin, study design, population, sample size, sleep measure used, cognitive measure used, pain and/or mood disturbance measure used, and main outcomes which met measures of effect criteria stated above and were relevant to the research questions.

Due to the infancy of this research topic and the heterogeneity of study designs, a narrative synthesis was deemed the most suitable approach to amalgamate and synthesise the results (Popay et al., 2006). The reporting was produced in accordance with the PRISMA reporting checklist (Moher et al., 2009).

## Quality Assessment

All remaining full-articles were assessed for quality and confidence in the evidence. 30% of these were independently assessed by EK.

Quality of the papers were assessed using the Mixed Measures Appraisal Tool (MMAT) (Hong et al., 2020), which produced a 1-5 star rating where, 5-stars indicates 100% quality criteria met, four-stars indicates 80% quality criteria met, three-stars indicates 60% quality criteria met, 2-star indicates 40% quality criteria met, 1-star indicates 20% quality criteria met, see Table 3 for quality rating and Appendix E for scoring system. This tool was selected due to the heterogeneity of study designs included in this review. Inter-rater reliability was calculated to be $K = 0.85$, 94% agreement.

The MMAT quality rating for the included studies ratings ranged from 2-5 five stars, indicating between 40-100% of quality criteria met and an overall good quality of included studies. There were, however, recurrent issues that compromised the quality of studies, which related to the measurement selection (mostly in relation to sleep quantity), management of confounders, sample sizing and sampling methods, and to a lesser extent the statistical analytical rigour.

Table 3 Mixed Measures Appraisal Tool (MMAT) quality assessment

| | Mixed Measures Appraisal Tool (MMAT) Methodological quality criteria | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Quantitative non-randomized | | | | | Quantitative Descriptive | | | | | | |
| **Author (Date)** | Are the participants representative of the target population? | Are measurements appropriate regarding both the outcome and intervention (or exposure)? | Are there complete outcome data? | Are the confounders accounted for in the design and analysis? | During the study period, is the intervention administered (or exposure occurred) as intended? | Is the sampling strategy relevant to address the research question? | Is the sample representative of the target population? | Are the measurements appropriate? | Is the risk of nonresponse bias low? | Is the statistical analysis appropriate to answer the research question? | **Star Rating** | **Comments** |
| Blaney et al., (2021) | Yes | Yes | Yes | NS | Yes | | | | | | **** | Unclear if confounds such as previous concussions were used as covariates in analysis despite there being a significant difference in frequency of concussion history between groups. |

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|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Bogdanov et al., (2019) | Yes | Yes | Yes | No | No | Yes | No | Yes | Yes | Yes | *** | Only N=3 mild TBI participants were recruited so were excluded from analysis. The intention had been to look at the impact of severity of TBI but moderate and severe TBI were instead collapsed into one group for correlational analysis. Pain and mood assessed as 'variables of interest' but not used as covariates in main analysis. |

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|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Brooks et al., (2019) | | | | | | Yes | Yes | Yes | Yes | No | **** | Alternative analysis such as moderation/ mediation or regression would have allowed for the relationship between variables to be assessed. The constructs measured were connected and you might expect there to be link between subjective and objective measures of cognition for example. |
| Câmara-Costa et al., (2020) **France** *** | Yes | Yes | Not Sure | No | Yes | | | | | | *** | Missing data acknowledged but not clear how this was managed. Mood disturbance assessed separately and could be a confound. |

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|---|---|---|---|---|---|---|---|
| | | | | | | | The BRIEF contains aspects of emotion regulation, mood disturbance could be a confound. |
| Cassimatis et al., (2023) | No | No | Yes | Yes | Yes | *** | Would have benefited from objective sleep measure such as actigraphy/polysomnography as defined groups based on sleep quantity/quality on self-report measures. |
| Dodd et al., (2020) | Yes | Yes | Yes | Yes | Yes | **** * | |
| Iyer et al., (2019) | No | No | Yes | Yes | Yes | *** | Would have benefitted from actigraphy/polysomnography as defined groups by less than 5 hours sleep |

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| | | | | | | | | | | | | but reliant on self-reported. Unequal participants in groups. Small control group. |
| Lah et al., (2021) | Yes | Yes | Yes | Yes | Yes | No | Yes | Yes | Yes | Yes | **** | Unequal sample size across groups. |
| Lequerica et al., (2022) | Not Sure | Yes | Yes | Yes | Yes | | | | | | **** | Small sample acknowledged. Did not specify the severity of TBI. |
| Madaan et al., (2021) | Yes | Yes | Yes | No | Yes | Yes | Yes | Not Sure | Yes | Yes | **** | Difference in internalizing found but not used as covariate in analysis. ROIs used in correlation analysis not justified. |
| Murdaugh et al., (2018) | Yes | Yes | Yes | Yes | Yes | Yes | Yes | No | Yes | Yes | **** | Sleep quantity relies on self-report of TBI participant. Subjective measure of a quantitative outcome. Could have been |

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|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | | | | | supported with actigraphy. |
| Riccardi (2024) | | | | | | No | Yes | Yes | Yes | No | *** | Small sample and no control group. Statistical rigour could be improved. |
| Riccardi et al., (2025) | | | | | | Yes | No | Yes | No | No | ** | Low attrition, small sample size and would have benefitted from a control group. Statistical rigour could be improved, limited sensitivity in analysis. |
| Shay et al., (2014) | Yes | Yes | Yes | Yes | No | Yes | Yes | Yes | Yes | No | **** | Total sleep problems predicted emotional and behavioural problems but emotional problems not used as covariate |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | | | | | | | when looking at neurocognitive functioning. Unequal groups with severity of TBIs separated. |
| Sufrinko et al., (2016) | Yes | No | Yes | Yes | Yes | **** | Would have benefitted from actigraphy/polysomnography as defined groups by less than 5 hours sleep (self-reported). |
| van Markus-Doornbosch et al., (2016) | No | Yes | Yes | Yes | No | *** | Uneven group sizes and small ABI group. Would have benefited from control Group |
| Williams et al., (2022) | No | Yes | Yes | Yes | Yes | **** | Would have benefited from a control group. |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| Yeo et al., (2021) | No | Yes | No | Yes | Yes | *** | Would have benefited from an objective measure of sleep (i.e., actigraphy or polysomnography). Small sample and no control group. |

1-5 star rating where, 5-stars indicates 100% quality criteria met, four-stars indicates 80% quality criteria met, three-stars indicates 60% quality criteria met, 2-star indicates 40% quality criteria met, 1-star indicates 20% quality criteria met. The overall quality of a combination cannot exceed the quality of its weakest component. Thus, the overall quality score is the lowest score of the study components.

Several studies comprised of small sample sizes (studies 8, 9, 12, 13, 18 in Table 3), which arguably limits the generalisability of the results. Several studies (12, 13, 17, 18) also would have benefitted from the inclusion of control groups. Study 13 also had a large degree of attrition, which likely impacted on the results and limits the sensitivity and statistical analysis approaches that would be appropriate. Issues with completing intended recruitment strategies was also present in study 2 which had to collapse TBI severity groups, which reduced the ability to evaluate the impact of TBI severity sensitively.

A central concern across numerous studies was the lack of acknowledgment of and statistical management of potential confounds. Several studies assessed mood disturbance (2, 4, 10, 14, 17), pain (2, 6, 18) but failed to integrate these into the findings despite previous research which has suggested that both mood disturbance and pain can impact on sleep and cognition. This limits confidence in causal inferences about sleep–cognition relationships.

The final, most prominent issue with quality was the reliance on self-report measures to assess 'sleep quantity' (5, 7, 15). These studies defined their groups based on degree of sleep quantity but neglected to include an objective measure of sleep (e.g., actigraphy or polysomnography) which significantly limited the confidence in group allocation. Although self-report sleep measures provide valuable insight into certain aspects of sleep and sleep behaviour, it is widely accepted that self-report estimation of sleep quantity is unreliable (Lauderdale et al., 2008)

## Results

### Study Selection

Database searches yielded 205 articles which were reviewed and assessed for eligibility after removal of duplicates, and excluded formats (i.e., brief reports or conference abstracts. Qualitative literature was included in the search, but all returned studies were quantitative. Therefore, no qualitative data was included. After application of inclusion and exclusion criteria, 18 studies were included in the narrative synthesis, see Figure 1. Table 3 summarises the key data extracted in accordance with the PRISMA guidance (2020).

Table 4 Data Extraction Summary Data (n=2903)

| **Identifier** | **Authors** (Year) **Country** Quality Rating from MMAT ***** for 100% quality criteria met **** for 80% quality criteria met *** for 60% quality criteria met ** for 40% quality criteria met * for 20% quality criteria met | **Methodology** | **Population** *n* = (TBI severity/SWD) Mean/Median age in years (± SD/IQR) Age range in years *n*= (Control/SWD) Mean age in years (± SD) Age range in years | **Sleep Measure** | **Cognitive Measure** (S/O - Subjective/Objective) | **Head injury severity** | **Potential Confound:** Measure (Controlled for Yes/No) | **Significant Outcomes** *Non-significant outcomes* |
|---|---|---|---|---|---|---|---|---|
| 1 | Blaney et al., (2021) **USA** **** | Cross-sectional | *n = 31* (mild TBI + SWD*)* *15.00* (± 1.79) 12-20<br><br>*n = 19* (mild *TBI)* *15.21* (± 2.62) *12-20*<br><br>*n = 19* (HC + SWD) *14.89* (± 2.21) *12-20*<br><br>*n = 31* (HC) *15.9* ± 2.10 *12-20* | PCSS | ImPACT (O) | Mild TBI | Previous mild TBI: assessed in history taking (No) | ↓ Verbal memory in mild TBI + SWD (difficulty falling asleep, sleeping more than usual, and/or sleeping less than usual) vs mTBI<br><br>↓ Visual memory in mild TBI + SWD (difficulty falling asleep, sleeping more than usual, and/or sleeping less than usual) vs SWD (difficulty falling asleep, sleeping more than |

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|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | | | | usual, and/or sleeping less than usual) |
| | | | | | | | | | | | ↓ Visual memory in mild TBI + SWD (difficulty falling asleep, sleeping more than usual, and/or sleeping less than usual) vs HC |
| | | | | | | | | | | | ↓ Visual-motor speed in mild TBI + SWD (difficulty falling asleep, sleeping more than usual, and/or sleeping less than usual) vs mild TBI |
| | | | | | | | | | | | ↓ Visual-motor speed in mild TBI SWD (difficulty falling asleep, sleeping more than usual, and/or sleeping less than usual) vs HC |
| | | | | | | | | | | | ↓ Reaction time in mild TBI + SWD (difficulty falling asleep, sleeping more than usual, and/or sleeping less than usual) vs mild TBI |

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| | | | | | | | | ↓ Reaction time for mild TBI +SWD (difficulty falling asleep, sleeping more than usual, and/or sleeping less than usual) vs HC |
| 2 | Bogdanov et al., (2019) **Australia** *** | Cohort study & Correlational | *n = 21* (moderate TBI) 11.77 (± 3.37) 6-16<br><br>*n = 21* (severe TBI) 10.09 (± 3.13) 6-15<br><br>*n* = 38 (OI) 10.32 (± 2.88) 6-15 | SDSC CSHS | CBCL (S) | Moderate or severe TBI | Mood disturbance: CBCL (No)<br><br>Pain: FPS-R (No) | ↑ SWD (difficulty initiating and maintaining sleep) in severe TBI vs OI<br><br>↑ SWD (excessive somnolence) in moderate TBI vs OI<br><br>Positive correlation between SWD (difficulty initiating and maintaining sleep) and attentional problems (TBI only)<br><br>Positive correlation between mood disturbance and initiating and SWD (maintaining sleep) |
| 3 | Brooks et al., (2019) **Canada** **** | Correlational | *n =121* (mild TBI) 16.2 (± 1.2) 13-18 | ISI | MEMRY (S) ADHD-5 (S) CNSVS (O) ChAMP (O) TOMM | Mild TBI | Mood Disturbance: BASC-2 (No) | Positive correlation between SWD (insomnia severity) and self-report memory problems.<br><br>Positive correlation between SWD |

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| | | | | | (O) | | | (insomnia severity) and parent-report attentional problems.<br><br>Positive correlation between SWD (insomnia severity) and self and parent report memory problems.<br><br>*Positive (non-significant) correlation between SWD (insomnia severity) and performance on neurocognitive assessment.* |
| 4 | Câmara-Costa et al., (2020)<br>**France**<br>*** | Longitudinal Cohort | *n* = 37 (severe TBI)<br>15.4 (± 4.4)<br>7-23<br><br>*n* = 33 (HC)<br>15.3 (± S4.5)<br>7-23 | PedsQL-MFS (French-validated version) (Sleep/Rest) | WISC-V (French version) (O)<br>WAIS IV (French versions) (O)<br><br>BRIEF (French adaptation) (S) | Severe TBI | Mood disturbance: CBCL (No) | ↑ EF concerns (parent-report) in Severe TBI vs HC<br><br>↑ Sleep/Rest fatigue concerns (self/parent report) in Severe TBI vs HC<br><br>IQ ↓ in TBI group vs HC |
| 5 | Cassimatis et al., (2023)<br>**Australia**<br>*** | Retrospective Cross-sectional | *n* = 554 (mild TBI)<br>13 (± 2)<br>6-18 | PCSS | ImPACT (O) | Mild TBI | | SWD (↓ Sleep quantity) associated with ↓ Verbal memory<br><br>SWD (↓ Sleep quantity) associated with ↓ visual memory |
| 6 | Dodd et al., (2020) | Longitudinal Cohort | *n = 30* (mild TBI)<br>15.6 (±2.2) | PROMIS | DKEFS (O) | Mild TBI | Mood disturbance: | ↑ SWD (difficulty falling/staying asleep, |

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| | **USA**<br>***** | | 12-18<br><br>*n =35* (HC)<br>15.5 (±1.9)<br>12-18 | | WAIS-IV<br>(O)<br>WRAT-4<br>(O)<br>WISC-V<br>(O)<br>Cogstate Battery<br>(O) | | PROMIS<br>(Yes)<br><br>Pain:<br>Pain rating 0-10 Likert scale<br>(Yes) | excessive somnolence) problems in mild TBI vs HC<br>*(No significant main effect of time)*<br><br>↓ processing speed for mild TBI group vs HC<br>*(No significant main effect of time)*<br><br>↓ attention for mild TBI group vs HC<br>*(No significant main effect of time)* |
| 7 | Iyer et al., (2019)<br>*** | Cross-sectional and Correlational | *n = 100* (mild TBI)<br>14.06 (±2.4)<br>-<br><br>*n = 20* (HC)<br>14.46 (±3.0)<br>- | PCSI | BRIEF<br>(S) | Mild TBI | Mood Disturbance: BASC-2<br>(Yes) | In mTBI group EF rating, age at injury, behavioural symptoms, SWD (trouble falling asleep, excessive somnolence, sleep quantity) associated with functional connectivity in frontoparietal and DMN.<br><br>*No significant group effect of functional connectivity* |
| 8 | Lah et al., (2021)<br>**Australia**<br>**** | Cohort and correlational | *n = 23* (moderate to severe TBI)<br>10.2 (±3.2)<br>5-15 | PedsQL-MFS<br>(Sleep/Rest) | PedsQL-MFS<br>(Cognitive Fatigue)<br>(S) | Moderate to severe TBI | | ↑ SWD (OLS) in TBI vs OI<br>*No significant correlation between* |

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| | | | *n* = 13 (OI)<br>10.2 (±2.8)<br>5-15 | SDSC<br><br>Actigraphy (TIB, OLS, WASO, TST, SE) | | | *SWD (OSL) and with Cognitive Fatigue*<br><br>↑ SWD (excessive somnolence) in TBI vs OI<br><br>↓ SWD (initiating and maintaining sleep) in TBI group vs OI<br><br>↑ Sleep/Reset fatigue (parent/self-report) in TBI group vs OI<br><br>↑Cognitive fatigue (parent/self-report) TBI group vs OI |
| 9 | Lequerica et al., (2022)<br>**USA**<br>**** | Cross-sectional | *n=14* (TBI)<br>13.5 (±3.0)<br>8-17<br><br>*n=16* (ABI)<br>12.2 (±3.0)<br>8-17<br><br>*n=14* (OI)<br>13.8 (±1.7)<br>8-17 | Actigraphy | WeeFIM (Cognitive subscale)<br><br>(S) | - | ↓ SWD (rest-activity ratio) in TBI group vs Patient Control group<br><br>↑ cognitive concerns in TBI group vs Patient Control group<br><br>Positive correlation between SWD (rest-activity ratio) and cognitive concerns<br><br>TBI vs Control Group difference in SWD (rest-activity ratio) non-significant when Cognitive concerns used as covariate. |

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| 10 | Madaan et al., (2021)<br>**India**<br>*** | Cross-sectional and correlational | *n = 74* (mild TBI)<br>9.5 (±2.7)<br>6-16<br><br>*n = 51* (HC)<br>9.4 (±2.8)<br>6-16 | CSHQ | WISC-IV (Indian adaptation)<br>(O) | Mild TBI | Mood disturbance: CBCL (No) | ↓ IQ in mTBI vs HC<br><br>↓ Perceptual reasoning in mTBI vs HC<br><br>↓ Processing speed in mTBI vs HC.<br><br>↑Clinical level SWD (bedtime resistance, sleep-onset delay, reduced sleep duration, sleep anxiety, night wakings, parasomnias, sleep-disordered breathing, and daytime sleepiness) prevalence in mTBI vs (12.3%) HC (2%) |
| 11 | Murdaugh et al., (2018)<br>**USA**<br>**** | Cross-sectional and correlational | *n* = 528 (mild TBI)<br>14.11 (±1.9)<br>10–18<br><br>*n* = 443 (HC)<br>15.3 (± 1.3)<br>10–18 | PCSS (sleep symptom cluster)<br><br>Sleep quality (self-report) | ImPACT<br>(O)<br><br>PCSS (Cognitive cluster)<br>(S) | Mild TBI | | SWD (↓sleep quantity) in TBI vs HC<br><br>↑ cognitive complaints in TBI vs HC<br><br>↓ performance in memory assessment in TBI + SWD (↓sleep quantity) group vs TBI + Typical/optimal sleep<br><br>↓ processing speed in TBI +SWD (↓sleep quantity) vs TBI +Typical/optimal sleep |

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| | | | | | | | | Negative correlation between SWD (sleep quantity) and report of cognitive complaints |
| 12 | Riccardi (2024)<br>**USA**<br>*** | Correlational | *n* = 15<br>(moderate/severe) TBI<br>10 (±1.59)<br>8-17 | PedsQL-MFS (Sleep/Rest) | BREIF (O) | Moderate /severe TBI | | Negative correlation between Fatigue and EF concerns |
| 13 | Riccardi et al., (2025)<br>**USA**<br>** | Longitudinal Cross-sectional | *n* = 17<br>(moderate/severe) TBI<br>-<br>- | BrainSTEPS (Sleep Issues) | BRIEF (O) | Mild/Moderate/severe TBI | | EF concerns at non-clinical level by 16-months post injury.<br><br>*No significant difference in EF concerns in those with SWD vs without SWD* |
| 14 | Shay et al., (2014)<br>**USA**<br>**** | Cross-sectional And longitudinal | *n* =55 (moderate TBI)<br>5.01 (±1.9)<br>3-6<br><br>*n* = 20 (severe TBI)<br>4.75 (± 0.9)<br>3-6<br><br>*n* =92 (OI)<br>5.15 (± 1.05)<br>3-6 | CSHQ | BRIEF (O)<br>ABAS (S)<br><br>NEPSY<br>(O)<br><br>DAS-II<br>(O)<br><br>Woodcock Johnson-III<br>(O) | Moderate /severe TBI | Mood disturbance: CBCL (No) | ↑ SWD (bedtime resistance, sleep-onset delay, reduced sleep duration,<br>sleep anxiety, night wakings, parasomnias, sleep-disordered breathing, and daytime sleepiness) in TBI (combined) vs OI<br><br>↑ SWD (reduced sleep quantity)<br>in TBI (combined) vs OI at 6- and 12-months post injury |

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| | | | | | | | ↑ SWD (Bedtime resistance) sTBI (combined) vs mTBI at 6-, 9- and 12-months post injury.<br><br>SWD (↓ sleep duration) in sTBI vs mTBI or OI<br><br>Positive correlation between SWD (sleep problems) EF concerns<br><br>*No significant relationships between SWD and neuropsychological test performance* |
| 15 | Sufrinko et al., (2016)<br>**USA**<br>**** | Cross-sectional | *n = 78* (mild TBI + SWD)<br>15.26 (±1.09)<br>4-17<br><br>*n* = 100 (mild TBI)<br>-<br>4-17 | PCSS | ImPACT (O) | Mild TBI | ↓ poorer neurocognitive on visual memory in mild TBI + SWD (↓ sleep quantity) vs mild TBI<br><br>↓ poorer neurocognitive on verbal memory in mild TBI + SWD (↓ sleep quantity) vs mild TBI<br><br>↓ reaction time in mild TBI + SWD (↓ sleep quantity) vs mild TBI |

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| 16 | van Markus-Doornbosch et al., (2016)<br>**Netherlands**<br>*** | Cross-sectional | *n* = 69<br>(moderate/severe TBI)<br>11 (7-19)<br>-<br><br>*n* = 19 (ABI)<br>14 (7-21)<br>- | PedsQL MFS (Sleep/Rest)<br>Dutch language version | PedsQL MFS (Cognitive) (S) | Moderate /severe TBI | | ↓Cognitive Fatigue in TBI vs ABI<br><br>*No difference in Sleep/rest Fatigue between TBI and ABI* |
| 17 | Williams et al., (2022)<br>**Switzerland**<br>**** | Cross sectional | *n* = 131 (TBI)<br>11.5 (7.4-13.8)<br>3 - 18 | SDSC | BRIEF (S)<br>WRAT-4 (O)<br>WRAT-5 (O)<br>CMS (O)<br>WAIS IV (O)<br>WISC-V (O)<br>ChAMP (O)<br>DKEFS (O) | Mild/Moderate/Severe TBI | Pre-injury mood disturbance: clinical note review (Yes) | 68% had clinically significant SWD (initiating/ maintaining sleep: 53%, sleep breathing:11% disorders, arousal:15%, sleep-wake transition: 31%, excessive somnolence: 10%, and hyperhidrosis:11%)<br><br>Negative correlation between SWD (initiation and maintaining sleep) EF concerns<br><br>Negative correlation between SWD (sleep-wake transition) and EF concerns<br><br>Negative correlation between SWD (excessive somnolence) and |

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| | | | | | | | | EF concerns<br><br>↑ EF concerns in TBI + SWD compared to TBI no SWD<br><br>Negative correlation between performance on cognitive assessment and SWD (excessive somnolence)<br><br>Negative correlation between performance on cognitive assessment and SWD (sleep hyperhidrosis)<br><br>*No significant group difference in performance on cognitive assessments between TBI +SWD vs TBI no SWD*<br><br>*No significant difference in mood disturbance between TBI +SWD vs TBI no SWD* |
| 18 | Yeo et al., (2021)<br>**Australia**<br>*** | Longitudinal | *n* = 21<br>(moderate/severe TBI)<br>13.7 (6.3-12.11)<br>8-18 | SDSC<br><br>PedsQL- MFS<br><br>(Sleep/Rest) | PedsQL MFS (Cognitive) (S)<br>PMQ (S)<br>CMQ (S) | Moderate to severe TBI | Mood disturbance: CBCL (Yes)<br>Pain: FPS-R | Positive correlation between SWD (initiating/maintaining sleep, excessive somnolence ) and Sleep/Rest fatigue. |

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| | | | | | | | Negative correlation between SWD (Initiating and Maintaining Sleep subscale) and CMQ (child-report)<br><br>↑ than normative SWD (initiating/maintaining Sleep and Excessive Somnolence) score at 5- and 7-years post-injury. |

Mild Traumatic Brain Injury (mTBI), Executive Functioning (EF); Sleep Wake Disorder (SWD), Executive Functioning (EF); Default Mode Network (DMN); CNS Vital Signs Neurocognitive Battery (CNSVS ); Delis-Kaplan Executive Function System (DKEFS); Differential Ability Scales – Second Edition (DAS-II)
Faces Pain Scale-Revised (FPS-R); Multidimensional fatigue scale (); Sleep Disturbance Scale for Children (SDSC); Multidimensional Fatigue Scale (PedsQL-MFS); Everyday Memory Rating in Youth (MEMRY), Children's *Memory Scale (CMS);* Child and Adolescent Memory Performance (ChAMP); Test of Memory Malingering (TOMM); *Delis-Kaplan Executive Function System (D-KEFS);* Interquartile Range (IQR); Post-concussive Symptom Scale (PCSS); Insomnia Severity Index (ISI); Time in Bed (TIB); Onset Latency of Sleep (OLS); Wake after Sleep Onset (WASO); Total Sleep Time (TST); Sleep Efficiency (SE); Parent Memory Questionnaire (PMQ); Child Memory Questionnaire (CMQ); Sleep Hygiene Index (SHI); Children's Sleep Habits Questionnaire (CSHQ); Immediate Post-concussive Assessment Cognitive Test (IMPACT); Health and Behavior Inventory (HBI); Orthopaedic Injury (OI); Wechsler Intelligence Scale for Children (WISC-IV); Functional Independence Measure for Children (WeeFIM); Wechsler Adult Intelligence Scale - Fourth UK Edition (WAIS-IV UK); Wide Range Achievement Test 4 (WRAT4); Wide Range Achievement Test, 5 (WRAT5)

## Study Characteristics

A total of 2903 participants took part across all the studies. 2062 were young patients with TBI. Eleven studies included control groups, and a total of 824 control participants took part across all the studies. Sample sizes ranged from *n* = 17 - 971. There was an age range of 3 – 23 years old age. See Table 4 for further participant demographics.

Table 5 - Participant Descriptive Statistics Across Studies

| Group | *Gross Mean Age Years; Months | *Gross SD | Age Range | N = Studies | *n* = Participant |
|---|---|---|---|---|---|
| *Mild TBI* | 13; 10 | 1.92 | 4-20 | 8 | 1635 |
| *Moderate/Severe TBI* | 9; 7 | 2.94 | 3-23 | 9 | 427 |
| *Healthy Control* | 14; 10 | 1.87 | 6-23 | 6 | 632 |
| *Orthopaedic Injury* | 7; 7 | 1.88 | 3-17 | 4 | 157 |

**Studies with no Mean (±SD) reported were excluded*

## Narrative Synthesis

## Nature of Sleep Health Disturbance experience by Child and Adolescent TBI populations

Sleep health was assessed using a range of subjective and objective, age-appropriate measures which are listed in Table 5. It was more common to use subjective measures of SWD (1, 2, 3, 5, 6, 7, 8, 10, 11, 13, 14, 15, 17 and 18) or the Multidimensional Fatigue Scale which provided subjective, parent-report rating of Sleep/Wake fatigue (4, 8, 12, 16 and 18). Only two studies (8 and 9) used physiological measures of sleep health such as actigraphy.

Higher levels of Sleep/Wake fatigue were reported (self- and parent- report) in TBI groups compared to controls (4, 8). Sleep/Wake Fatigue was lower however, in TBI compared to ABI (16). Higher levels of Sleep/Wake were also associated with higher incidence of SWD, including difficulties initiating and maintaining sleep and excessive somnolence (18).

One study (17) reported on the incidence of clinically significant SWD within the TBI population. This was reported as 68%, with initiating/maintaining sleep the most common form (53%), followed by difficulties with sleep-wake transitions (31%).

SWD were present across all TBI severities (mild-severe) and studies which characterised SWD were convergent on the indication of difficulty initiating sleep and maintaining sleep, and excessive somnolence *(*1, 2, 8, 10, 14, 17, 18). Disruption in sleep continuity and group differences in rest–activity pattern was also reported in both studies which utilised objective measures SWD (8 and 9). It is important to note, however, that both studies utilising objective measures of sleep (8 and 9) had very small sample sizes, which reduces their generalisability. Longitudinally it was indicated that certain aspects of SWD such as initiating/maintaining sleep and excessive somnolence persisted years after the initial TBI (18)

Sleep related behaviours such as bedtime resistance were also reported to be higher in incidence in the TBI group compared to controls (10,14).

Table 6 - Summary of Measures Used to Assess Sleep

| Full Title | Abbreviation | Domains Assessed | Age Range | Frequency | Reference |
|---|---|---|---|---|---|
| Actigraphy (Objective Sleep Monitoring) | Actigraphy | Sleep-wake patterns (activity based) | 1+ | 2 | (Paediatrics & Health, 2009) |
| Post-Concussion Symptom Scale – Sleep Items | PCSS | Difficulties falling/ staying asleep, excessive somnolence and sleep quantity | 2+ | 5 | (Lovell et al., 2006; Podolak et al., 2021) |
| Sleep Disturbance Scale for Children | SDSC | Difficulties falling/staying asleep of sleep, breathing disorders, arousal, excessive somnolence | 3–18 | 4 | (Bruni et al., 1996; Romeo et al., 2013) |
| Children's Sleep Habits Questionnaire | CSHQ | Bedtime behaviour, sleep duration, night wakings, parasomnias, sleep-disordered breathing | 2-16 | 2 | (Owens et al., 2000; Sneddon et al., 2013) |
| Insomnia Severity Index | ISI | Sleep onset, maintenance, dissatisfaction, disturbance, severity | 5+ | 1 | (Denis et al., 2023; Morin et al., 2011) |
| PedsQL Multidimensional Fatigue Scale | PedsQL-MFS (sleep/rest) | Restorative sleep, daytime tiredness, sleep-related fatigue | 2–18 | 5 | (Varni et al., 1998, 2002) |
| Pediatric Sleep Disturbance & Sleep-Related Impairment | PROMIS | Difficulty falling/staying asleep, excessive somnolence | 5–17 | 1 | (Forrest et al., 2018) |

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|---|---|---|---|---|---|
| Post-Concussion Symptom Inventory – Sleep Items | PCSI | Difficulty falling/staying asleep, excessive somnolence | 5–18 | 1 | (Sady et al., 2014) |

**Nature of subjective neurocognitive problems in children and adolescent populations post TBI**

Subjective neurocognitive function was assessed using a wide range of age-appropriate parental and self-report questionnaires post TBI, see Table 6.

Two studies included child/adolescent self-report measures of specific neurocognitive concerns such as memory (3 and 18), others relied on parent-report measures.

Self-report measures of neurocognitive concerns indicated the presence of memory concerns in TBI populations (3 and 18). Parent report of neurocognitive concerns generally (11) and in terms of specific cognitive domains such as attention and memory, endorsed neurocognitive concerns (2 and 3). Study 1 included non-corroborating neurocognitive testing. Study 3 did not include objective neurocognitive measures.

The most common subjective neurocognitive concern was parent-report executive functioning concerns which were evident in four studies (4, 12, 14 and 17). These were all with populations of moderate to severe TBI. This suggests parental concerns around EF are common in this population, but we cannot generalise to mild TBI populations. One study (17) also reported a link between subjective executive functioning concerns and functional connectivity in frontoparietal networks and the DMN.

Despite the common occurrence of parent-report executive functioning concerns, longitudinally, parent-report ratings indicated executive functioning had returned to within a non-clinical range by 16-months post injury (14). This could indicate that although present in the early stages after TBI, executive functioning deficits resolve. It is important to note however; this study was not supported with objective measures of executive functioning or functional measures which limits the conclusions which can be drawn between executive function concerns and executive functioning performance at this stage of recovery.

**Nature of objective neurocognitive difficulties experienced by children and adolescents post TBI**

Neurocognitive function was assessed using a wide range of age-appropriate neurocognitive tests, see Table 6. A range of cognitive domains were assessed including general reasoning abilities - Intelligence Quotient (IQ), memory (visual and verbal), attention, executive functioning (EF), and visuo-motor/processing speed. Despite there being subject reports of cognitive difficulties across domains of memory, executive functioning and attention, there was limited support for differences in performance on neurocognitive assessment for the TBI population.

Two studies (4, 10) looked at group comparisons between TBI and HC in terms of general reasoning (IQ) abilities, and found the TBI group performed significantly poorer compared to HC (4 and 10). Both these studies had age-matched control groups supporting confidence in this finding.

Slower speed of processing in TBI compared to HC was consistent across four studies (1, 6 , 10 and 11). These studies varied in TBI severity ranging from mild-moderate, indicating this finding was consistent across TBI severity. These studies also had age-matched control groups supporting confidence in this finding. Poorer performance on assessment of memory was also evident in one study which compared mild TBI groups with HC (1).

Despite there being subjective complaints of executive functioning difficulties (4, 12, 14 and 17), this was not reflected in neurocognitive testing. EF was assessed in two studies (6 and 17). Neither study found TBI specific difficulties. One study (6) did however find a significant difference in terms of attention in mild TBI compared to HC. Neurocognitive testing was completed with mild TBI however, and subjective complaints were collected across all severities. It could be that EF difficulties are more common in moderate-severe TBI.

Table 7 - Summary of Measures used to assess Cognition

| *Objective Measures* | **Full Title** | **Abbreviation** | **Domains Assessed** | **Age Range** | **Frequency** | **Reference** |
|---|---|---|---|---|---|---|
| | Child Memory Scale | CMS | Memory, Attention, Learning | 5-17 | 1 | (Cohen, 1997) |
| | CNS Vital Signs Neurocognitive Battery | CNSVS | Attention, EF, processing speed | 7+ | 1 | (Gualtieri & Johnson, 2006) |
| | Child and Adolescent Memory Profile | ChAMP | Immediate and delayed verbal/visual memory | 5–21 | 2 | (Sherman & Brooks, 2015) |
| | Cogstate Computerised Cognitive Test Battery | Cogstate | Processing speed, attention, learning | 6+ | 1 | (Maruff et al., 2009) |
| | Delis-Kaplan Executive Function System | DKEFS | Executive functions | 8+ | 2 | (Delis et al., 2001) |
| | Differential Ability Scales – Second Edition | DAS-II | General cognitive ability | 2;6-17;11 | 1 | (Elliott et al., 2007) |
| | Immediate Post-Concussion Assessment and Cognitive Testing | ImPACT | Memory, processing speed, reaction time | 5+ | 4 | (Ibarra, 2011) |
| | NEPSY–Second Edition | NEPSY-II | Attention, EF, memory, language | 3-16;11 | 1 | (Kemp & Korkman, 2010) |
| | Test of Memory Malingering | TOMM | Effort/memory validity | 16+ | 1 | (Tombaugh & Tombaugh, 1996) |
| | Wechsler Adult Intelligence Scale – Fourth Edition | WAIS-IV | IQ, working memory, processing speed | 16+ | 1 | (Wechsler, 2008) |
| | Wechsler Intelligence Scale for Children – Fourth/Fifth Edition | WISC-IV / WISC-V | IQ, working memory, processing speed | 6-16;11 | 3 | (Wechsler, 2003, 2014) |
| | Wide Range Achievement Test – | WRAT-4 / WRAT-5 | Reading, spelling, arithmetic | 5+ | 2 | (Wilkinson & Robertson, 2017; |

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|---|---|---|---|---|---|---|
| | Fourth/Fifth Edition | | | | | Wilkinson & Robertson, 2006) |
| | Woodcock-Johnson Tests of Cognitive Abilities – Third Edition | WJ-III | Cognitive and academic clusters | 2+ | 1 | (Woodcock et al., 2001) |
| *Subjective Measures* | Behavior Rating Inventory of Executive Function | BRIEF / BRIEF-2 / BRIEF-P | Executive functioning (parent/teacher/self-report) | 2+ | 6 | (Gioia et al., 2000) |
| | Child Memory Questionnaire | CMQ | Memory concerns (parent/self-report) | 5-12 | 1 | (Drysdale et al., 2004) |
| | Child Behavior `Checklist | CBCL | Internalizing/Externalizing Behaviors, and Attentional/Hyperactivity concerns (parent-report) | 1;5-18 | 5 | (Achenbach & Rescorla, 2001) |
| | Multidimensional Everyday Memory Ratings for Youth | MEMRY | Memory, learning, and executive function concerns (parent-report) | 5-21 | 1 | (Sherman & Brooks, 2017) |
| | PedsQL Multidimensional Fatigue Scale Cognitive Subscale | PedsQL Cognitive Fatigue | Cognitive fatigue concerns (parent-report) | 2-18 | 2 | (Varni et al., 1998, 2002) |
| | Parent Memory Questionnaire/ Child Memory Qustionnaire (Parent/Child) | PMQ/CMQ | Memory concerns (self-report) | 5-18 | 1 | (Kadis et al., 2004) |
| *Functional Measures* | Functional Independence Measure for Children – Cognitive Scale | WeeFIM Cognitive | Functional memory, communication, problem solving concerns (parent-report) | 0;6-21 | 1 | (Msall et al., 1994) |

**Nature of associations between sleep and neurocognitive problems in children and adolescent populations post TBI**

Both subjective ratings of SWD (3, 11, 14) and objective measures of SWD were strongly associated with subjective cognitive concerns (9). Subjective SWD (5, 6, 11 and 15) was also shown to correspond with objective neurocognitive measures of speed of

processing, memory (5, 6, 9, 11 and 15). Specifically, TBI in conjunction with SWD was shown to lead to poorer slower speed of processing (1, 11 and 15). This suggested that SWD hinders speed of processing beyond the effects of mild TBI alone. TBI in conjunction with SWD was also shown to lead to poorer performance on memory (1, 5, 11 and 15); which again suggests SWD hinders this cognitive function beyond the effect of TBI alone. This additive effect of TBI and SWD appeared to be domain specific, however, as the one study (17) which determined groups based on SWD and assessed general reasoning abilities (IQ) did not find a significant difference between TBI groups with and without SWD. All of the studies were completed with mild TBI populations which means it is not possible to generalise conclusions across severities from this data alone.

SWD was also shown to correlate with subjective measures of attentional concerns (2) but there was no direct objective data on attentional performance to support this. One study (11) demonstrated both higher rates of SWD in their TBI population and poorer performance on objective measure of attention but did not directly link SWD with cognitive performance.

General cognitive fatigue was prominent, with several studies indicating elevated levels reported for the TBI populations across moderate to severe TBI (8, 12, 16, 18); and was specifically linked to subjective executive functioning (12).

Sleep/Wake fatigue and SWD was shown to negatively impact on subjective ratings of executive functioning (12, 14 and 17). Where objective neurocognitive data was collected alongside the subjective executive functioning rating, the data did not support the link between SWD and poorer executive functioning performance (17).

It was common to assess for mood disturbance, with eight studies doing so (2, 3, 4, 6, 7, 10, 17 and 18). Four studies also assessed for pain (2, 6, 8 and 18). Few studies controlled for these factors as potential confounds in their analysis, however. For those that did, significant associations between SWD and cognition remained (6, 18 and 17). This adds weight to the results above pertaining to link between post TBI SWD and neurocognitive function which is not merely driven by post TBI mood disturbance or pain.

## Discussion

Overall, the results indicate SWD are common in child and adolescent TBI populations across TBI severities. These results are in keeping with adult TBI literature in

terms of prevalence and occurrence across TBI severity (Albrecht & Wickwire, 2020; Aoun et al., 2019; Ayalon et al., 2007; Barshikar & Bell, 2017; Grima et al., 2016; Mathias & Alvaro, 2012; Orff et al., 2009; Wickwire et al., 2018). The results suggest a larger SWD prevalence than had previously been reported in paediatric TBI populations (Luther et al., 2020), however. Complimenting previous findings, the results suggest that initiating/maintaining sleep, excessive somnolence and difficulties with sleep-wake transitions are the most common form of SWD in this child and adolescent TBI populations.

Importantly, results from the synthesis indicate that TBI *in conjunction* with SWD negatively impacts on speed of processing, memory and elevates attentional and executive functioning concerns beyond TBI sequalae alone. These results are in accordance with adult literature which has indicated post TBI cognitive changes across memory, processing speed, attention and executive functioning (Bloomfield et al., 2010; Duclos et al., 2015; Theadom et al., 2015; Wiseman-Hakes et al., 2013) but importantly, suggest SWD is not only present but exacerbates cognitive dysfunction in child and adolescent TBI populations as difficulties in these cognitive domains were not only present in comparison to health controls but also TBI populations without SWD.

The results are therefore accordance in with adult literature that has indicated cognitive functions such as attention, memory and executive functioning are particularly susceptible to synergistic interplay between sleep dysfunction and TBI sequalae as these were the affected cognitive domains (Sanchez et al., 2022; Thomas, 2021). Unfortunately, none of the studies reviewed directly assessed any of the proposed mechanisms for cognitive disruption (Thomas, 2021) so cannot corroborate from a mechanistic perspective.

It is important to acknowledge that it was not possible to determine from the literature reviewed what determined the presence of SWD within the TBI population. It was therefore not possible to determine the direction of relationship between SWD and cognition difficulties; whether SWD causally impacted on cognition, or whether cognitive impairment hindered good sleep hygiene.

Overall, the results from the synthesis are concordant with previous literature within paediatric TBI and in adult TBI literature. The results also expand on previous findings in terms of characterising the nature of child and adolescent post TBI SWD and associated neurocognitive difficulties and concerns.

**Limitations**

The number of available studies, as well the lack of homogeneity of population characteristics, as well as the range of study designs and measures employed, are clear limitations of this narrative synthesis. As this research area is in its infancy there are no routine assessment batteries employed to assess sleep health and neurocognition in parallel.

The literature reviewed included a range of designs however the lack of baseline pre-injury data was an overarching limitation. Of note, no studies included baseline (pre-injury) neurocognitive assessment data. The lack of concrete baseline data is problematic as poor neurocognitive performance or ratings of cognitive complaints could reflect pre-existing difficulties but which are mistakenly misattributed to the TBI. One potential solution to this issue could be include data pertaining to attainment in school prior to TBI as this is readily collected across non-clinical samples and would provide an indication of normalised pre-morbid functioning. Importantly where associations were reported it is not possible to determine the direction of association.

Rarely were both subjective and objective measures of sleep employed. Future research utilising both forms could be beneficial as this would offer a more comprehensive assessment of sleep and the use of actigraphy would reduce the impact of unreliable historians, especially as this would reduce the reliance on self-report estimates of sleep provided by child and adolescent TBI populations. Moreover, longitudinal designs including sampling from multiple time points with both objective and subjective sleep and cognitive measures are likely to be of benefit as this would allow for the progression of symptom presentation to be characterised allowing inferences to be made regarding neurodevelopment.

Other factors such as pain and mood have been shown to relate to sleep and cognition but were not routinely assessed or controlled for across all studies. These could therefore be potential confounds. Further examinations of these relationships longitudinally may help inform our understanding of the interweaved mechanisms for sleep health disturbance, associated neurocognitive functioning, mood and pain.

The Multidimensional Fatigue Scale, which assessed cognitive fatigue was commonly utilised to indicate neurocognitive concern in the TBI populations. It is important to note that it is not clear specific cognitive functions this may relate to and impact on functioning is unclear. Further research to explore this in more detail would be of benefit as cognitive fatigue could relate to a range of cognitive domains and elucidating which specifically, would

allow for more tailed interventions to be devised and employed for the paediatric TBI population.

The protocol, as agreed with the University of Oxford Doctorate of Clinical Psychology Project Approval Session panel, was adhered to (Appendix A), but I omitted to submit the completed form for registration with PROSPERO. This is a limitation as this would have provided further transparency and improved credibility. Registration is not a pre-requisite for the intended journal; however, registration would have improved visibility of the study. Registration would also have reduced the risk of a duplicated review being commenced by another researcher. In future I would prioritise registration of a review protocol with PROSPERO.

**Recommendations**

The results from the synthesis suggest that clinically it would be of value to routinely screen for SWD in child and adolescent TBI populations. Subjective measures may also be complimented with the use of actigraphy where possible. To support this process, Paediatric Neuropsychology services could facilitate multi-disciplinary approach and link with Paediatric Sleep services.

Given the high likelihood of a child or adolescent with a TBI experiencing some form of SWD it could be of value to provide families with child or adolescent TBI's resources, which normalise SWD challenges and provide evidence-based recommendations to support good sleep hygiene.

Given the interplay between SWD and neurocognitive difficulties, it may be beneficial for schools to be provided with psychoeducation sessions around appropriate adjustments to workload, testing, and rest breaks for supporting child and adolescents post TBI in education.

Future research could also enrich the current understanding of sleep health and neurocognitive functioning in child and TBI populations. The literature reviewed included a wide range of ages, who were assessed with age-appropriate assessment, but it would be of value to explore if certain developmental periods heighten susceptibility to sleep-related cognitive sequelae post-TB. It may be that certain age groups are suspectable to domain specific disruptions; executive functioning deficits may emerge at later age for example.

Future research completed with matched groups of TBI populations with varying TBI severity and SWD could help elucidate whether there is a severity specific effect for SWD and neurocognitive difficulties within TBI populations.

Finally, it was beyond the scope of this study to explore systemic factors which could impact on sleep and neurocognitive functioning in child and adolescent TBI populations. Considering factors such as socioeconomic status and cultural difference in sleep practices could also be of value to explore in the future.

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**Service Improvement Project**

# Proportion and Experience of Autistic Service Users within an Outpatient Pelvic Pain Service

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## Abstract

Compared to the general public, autistic individuals have a higher incidence of comorbid physical health problems and psychological difficulties. Important disparities also exist in terms of access to, and experience of, healthcare. Autistic service users often report poorer healthcare accessibility and engagement.

An audit of autism prevalence was conducted with the John Radcliffe, Pelvic Pain Service (PPS), an outpatient service supporting both the physical and psychological health needs of women with pelvic pain. The aim of the audit was to identify the proportion of autistic service users accessing the PPS between December 2020-December 2022.

Semi-structured interviews were also carried out with $N = 5$ female autistic PPS service users (identified through the audit), to explore their experience of key aspects of the PPS including the materials/methods of information communication, initial multidisciplinary assessment and group sessions offered.

The audit revealed the PPS has a larger proportion of autistic women than there are in the general population. Thematic analysis revealed key themes around power, communication style, expectations and practical arrangements which impacted service users' accessibility, experience and engagement with the PPS. These findings led to recommendations, supported by the PPS, to develop video walk throughs of key aspects of the service, ensuring communication style is direct, and reflects respect, compassion and non-judgment and to promote service users' sense of agency and control, create suggested engagement guidelines for group interventions, and to consider options for offering service users alternative places to wait for appointments to reduce sensory overload.



**Key Words:** *Autistic, Pelvic Pain, Thematic Analysis, Healthcare, Service Improvement*

## Background

### *Autism Prevalence*

Autism Spectrum Disorder (ASD) is a lifelong, neurodevelopmental, condition defined in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) as impairments in social communication/interaction, sensory sensitivities, and the presence of restricted or stereotyped behaviours, which significantly hinder core aspects of daily functioning (American Psychiatric Association , 2013). The term autism will be used henceforth, as it neuroaffirming (Bottini et al., 2024) and aligns with the language used by the service users who participated in this study and the National Institute for Health and Care Excellence (NICE) commissioned guidance on supporting autistic adults, published by the National Collaborating Centre for Mental Health (NCCMH) (NCCMH, 2023).

In the United Kingdom (UK) autism prevalence is estimated to be 1.1% in adults (NCCMH, 2023), and is more commonly diagnosed in males than females, with an estimated radio of 4.2:1 (Loomes et al., 2017). NCCMH guidance posits clinicians be mindful that autism is 'under-recognised' in women (NCCMH, 2023) and may be masked (Milner et al., 2019). Further research working with autistic women to broaden our understanding of autism in this specific population is therefore needed (Green et al., 2019).

### *Autism and Healthcare*

Compared to the general public, autistic individuals have a higher incidence of comorbid physical health problems (Cashin et al., 2018) and psychological difficulties (Lever & Geurts, 2016). There are also important disparities in healthcare experience for autistic service users in the UK (Weir et al., 2022). Communication, sensory considerations and logistical management of care are considered common barriers to positive autistic patient experience (Mason et al., 2019). Autistic service users report more challenges than non-autistic service users in communicating how symptoms present in their own body, and higher rates of sensory overload during appointments (Weir et al., 2022).

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Positive outcomes in terms of patient satisfaction and dropout rates have however, been demonstrated in health care settings where autism informed accommodations to the environment and communication styles have been made (Loizou et al., 2024).

### *Autism and Pain*

It has been argued that autistic individuals present with an atypical pain experience in terms of pain sensitivity, attributed to sensory sensitivity (Clarke, 2015), and in pain reporting, attributed to poor interoceptive awareness and challenges in communication (DuBois et al., 2016; Failla et al., 2020). Indeed, poor communication can be a barrier to sensitive assessment and appropriate treatment of pain (Gregory, 2012; Nicolaidis et al., 2015); it is therefore vital to consider when working with autistic service users for whom communication with healthcare providers may already be a challenge (Nicolaidis et al., 2015; Liu et al., 2020).

### *Chronic Pelvic Pain*

Barriers to effective communication of, and accurate assessment of, pain is also reported by those who experience Chronic Pelvic Pain (CPP) (Bullo, 2020), who report a protracted journey to diagnosis, and note that they often feel ‘dismissed’ (Cox, Henderson, Andersen, Cagliarini, & Ski, 2003).

Autistic women with CPP are therefore likely to experience the interplay between these two conditions, have idiosyncratic, unique needs and may have a suboptimal service experience.

## The Service

The John Radcliffe Pelvic Pain Service (PPS) is a specialist outpatient service that supports women with the treatment and management of CPP symptoms. The PPS comprises a Multi-Disciplinary Team (MDT) of Gynaecologists, General Practitioners with Specialist Interest (GYSI), Clinical Psychologists, specialist Physiotherapists, and a Counsellor. The PPS offers MDT assessment clinics and group interventions, medical gynaecology

appointments, specialist physiotherapy sessions (one-to-one and group-based), and psychological support (one-to-one and group-based intervention).

*Role of Service in Project Development*

The PPS clinicians noted it was their impression that there was an overrepresentation of service users who presented with features associated with autism, such as difficulties with social communication and interactions, sensory sensitivity, and behaviours or mannerisms such as 'stimming' or redirection of discussion during sessions to a particular topic of intense interest.

The team identified the following areas of challenge this posed for service user engagement and experience:

- Difficulties with interactions during the MDT assessment and subsequent treatment sessions, which led to heightened levels of distress or frustration on the part of the service users.
- Communication break downs between service users and PPS team members with greater than usual incidents of misunderstandings that compromised rapport.
- Perceived challenges with service users' ability to communicate their pain experience clearly to the team, which led to a difficulty in the team's understanding of the person's pain and ability to determine appropriate treatment. This was particularly evident when service users were asked to use certain assessment materials such as pain rating scales.
- Higher rate of cancellations, disengagement, or abrupt ending of sessions and/or longer episodes of care than was typical for the service.
- A reluctance to attend the group-based interventions offered, which form a core part of the PPS provision.
- Uncertainty around autism prevalence within this service user population, and lack of clarity about specific accommodations that should/could be implemented to support optimal practice for these service users.

It was agreed that an audit of the proportion of autistic service users accessing the PPS would help determine if the staff impression of an over-representation of autistic service users was accurate. Although good practice in supporting autistic women means making appropriate adaptations as needed (NICE, 2021), a higher than typical proportion of autistic service users accessing the PPS would further underscore the importance of doing so. A more accurate impression of the proportion of autistics service users accessing the PPS could also inform appropriate allocation of resource to the development of any autism specific resource.

In addition, it was agreed with the PPS MDT that conducting semi-structured interviews with autistic service about their experience of the PPS could guide the types of adaptations to implement as there is no benchmark within pain services for working with those with comorbid autism and CPP. This method was also felt to align with the NICE guidance highlighting the importance of supporting autistic service users to facilitate autonomy and choice in their care decisions (NICE, 2021).

The PPS Psychologists and the Consultant Gynaecologist identified aspects of the service they felt may be being experienced differently by autistic service users. This was based on their experience, clinical impression and observed behaviours (as described above). The areas identified were also aspects of the service they felt there would be capacity to adapt and optimise for autistic service users. The areas identified were: materials/methods of communicating information, the multidisciplinary team initial assessment, and group-based interventions.

## Aims and Objectives

- The first aim in the project was to identify the proportion of patients accessing the PPS between December 2020 and December 2022 with a known or self-identified autism diagnosis who were assessed within the Multi-Disciplinary Assessment Clinic at the PPS, John Radcliffe, and to determine how this compares to the prevalence rates reported for the general population.
- The second aim was to work with PPS service users identified as being autistic to explore their experience of the following aspects of the PPS: initial MDT assessment,

materials/methods of information communication, and group interventions. Insights gained from the experience of these service users would inform specific service recommendations to improve engagement and experience of the aforementioned aspects of the PPS for autistic service users.

*Questions to be Addressed*

1 Is there an over representation of autism within the PPS compared to the prevalence of autism within the general population?
2 How could the materials/methods of information communication, MDT assessment and group provisions be improved/optimised for autistic service users?

## Method

*Role of Service Users in Project Development*

The interview schedule was developed through discussions with the stakeholders within the PPS initially to ensure it addressed the key aspects of the service they wanted to and felt they had capacity to improve. An expert by experience, identified by the Consultant Clinical Psychologist within PPS, was consulted prior to commencing the study. The demographics of the expert by experience were in keeping with a common intersection of demographics of the PPS service users (assigned female at birth, White-British, working-age adult, with English as a first spoken language). The expert by experience was consulted specifically on the prompts and language used in the semi-structured interview questions to be used with autistic service users. They made recommendations for amendments to ensure clarity in language used and also confirmed that they approved of the aspects of PPS service to explore during the interviews.

*Governance Issues and Ethical Approval*

The HRA decision tool indicated no IRAS application was not required, as service user involvement in the interviews was in conjunction to treatment as usual and would not produce generalisable findings. The interviews also asked about the experience of the service rather than personal experiences of pain.

The project was registered with the Oxford University Hospitals NHS Foundation Trust clinical governance system (Ulysses) and was approved as an internal audit, see Appendix A.

The proposed study did not pose any significant ethical issues. Any distress in describing negative experiences, or concerns raised in terms of significant unmet need identified, were relayed back to the service through the lead Clinical Psychologist who agreed to contact the service user to address any issues.

*Procedure*

The project had an initial audit phase and a secondary qualitative phase to address both project questions.

An audit was completed for a 24-month period (Dec 2020-Dec 2022). This period was determined by the length of time where the MDT assessment clinic had been running with all disciplines present. All associated notes and clinic letters from initial MDT assessments were reviewed from a clinic list provided by the service. The audit was completed to identify autistic service users through either confirmed autism diagnosis or the mention of self-identified autism in notes pertaining to or clinic letter from initial assessment.

Autistic service users identified through the audit were sent an invite letter to participate in a semi-structured interview to facilitate a service improvement project (see Appendix B). A follow-up phone call was completed following the letter being sent one week later to discuss participation if no response had been received.

If participants opted in for participation, an online meeting was arranged at their convenience using MS Teams. A semi-structured interview schedule was then followed to complete the interview with the service user (see Appendix C). The interview was audio recoded on a separate device for subsequent transcription.

*Participants (Audit Phase)*

The notes for all service users who had an MDT initial assessment between the specified timeframe were reviewed. No participants were excluded.

*Participants (Qualitative Phase)*

*Inclusion Criteria*

- Service users for whom there was mention of either self-identified autism or confirmed autism diagnosis in notes or initial assessment clinic letter.

*Exclusion criteria*

- Significant risk issues e.g., child protection issues ongoing
- Medically unstable e.g., currently recovering from surgery
- Under 18 years of age

*Data management*

Anonymised audit data and anonymised interview transcripts were transferred securely from OUH OneDrive to Nexus OneDrive for Business for storage and analysis.

*Analysis strategy*

Microsoft Excel was used to compute percentages and descriptive statistics for the audit data.

Interview scripts were analysed in 2023 using realist, inductive Thematic Analysis (TA) and the Braun and Clarke six-stage approach to analysis (Braun & Clarke, 2006). This approach was selected so that the service recommendations could be developed to reflect the true nature of the lived experiences of the service users and their perceptions of the service, with identified themes grounded in the rich language used by the service users (Nowell & Albrecht, 2019).

All stages of analysis were conducted by a single researcher. The process involved the following steps, consistent with Braun and Clarke (2006):

Familiarisation with the data:

Verbatim transcription of the audio recordings was completed. Transcripts were reviewed by the researcher alongside the recordings as part of familiarisation process and to identify and correct for any mistakes. Each transcript was then read in full several times to develop an understanding of the content. Notes were generated alongside to capture impressions and potential points of interest.

Generating initial codes:

A word was chosen to reflect each meaningful line of data. This was done systematically using open-coding to retain the data driven, inductive approach. Codes could be a direct word or phrase from that line or a word or phrase which summarised the key concept.

Searching for themes:

The codes were then reviewed to identify themes and patterns of concepts which would help answer the research questions. These phrases resulted in subthemes and identification of potential overarching themes.

Reviewing themes:

The themes were then reviewed with the aim of selecting between 3-5 overarching themes. This process was facilitated through reviewing the themes alongside the codes and direct quotes from participants in order to understand the relationships among themes and to ensure they remained grounded in the experience of the service users.

Defining and naming themes:

Each theme name was chosen to capture the core meaning ensuring relevance to the research aims/questions. The significance and narrative for the relationship between themes was then developed in relation to the research aims/questions. Exemplar quotes were compiled to support this process.

Reporting/dissemination:

The overarching themes were used as core topics of discussion with the MDT to develop the agreed upon recommendations. Each overarching theme was presented to the

team by the researcher visually, as an important area to focus on. The team were also presented with the associated subthemes, illustrative quotes and potential recommendations suggested by the researcher. Where the interviewees made direct requests or gave specific recommendations these were included in the recommendations.

Key recommendations to implement were agreed upon with the team. A table summarising the overarching themes, subthemes, supporting quotes and associated recommendations was produced. The analysis and recommendations were also written up in a summary report alongside a discussion, limitations and a lay summary.

With acknowledgement that with an inductive approach it is important to ensure systematic and trustworthy analysis, strategies to facilitate rigour were considered (Nowell & Albrecht, 2019). Table 1 summarises the strategies recommended, and actions taken in accordance with these strategies.

Table 1 Strategies for ensuring Rigour (Nowell & Albrecht, 2019, *p.* 359) and actions taken summary

| Phase | Suggested Strategy for Rigour | Action taken |
|---|---|---|
| Data Collection | Prolonged engagement with the setting | This was facilitated through the primary researcher having been on placement at the PPS prior to completing study which allowed for familiarisation with the service and service users. Contact and engagement with the service was also maintained following the end of placement through the attendance of local specialist interest groups on pain and somatic symptoms. |
| | Peer debriefing and documentation during data collection | Emma Evans (Consultant Clinical Psychologist at PPS) was consulted throughout the data collection process to discuss logistics of data collection and problem solve around cancellations/DNAs. |
| | Member check initial interpretation with informants during interviews through interpretative paraphrasing | Member interpretation check carried out with the use of verbal feedback during the interviews. Brief summaries of responses were provided during the interview with the service user being asked if this was correct. |

| | | |
|---|---|---|
| Analysis phase | Look for alternative interpretations and negative cases; describe prevalence of converging and diverging patterns | An effort was made throughout the analysis phase to consider alternative interpretations and negative cases process before determining a theme this was particularly useful when considering polarised experiences described by service users (e.g., being challenged being believed.) |
| | Member check findings with setting insiders | The recommendations were developed through discussion with the MDT using the raw data. |
| Reporting | Report design features aimed at improving rigor. | Actions taken to improve rigor tabulated for clarity to the reader around measures taken. |
| | Description of major findings are "grounded" in examples and/or illustrative quotations/text excerpts | The major findings are written with exemplar quotes and supported by a summary table which presents the illustrative quotes alongside the recommendations so as to ground them in the words of the service users. |

## Results

*Phase One: Audit Phase*

Participants ranged in age from 22-44 years (M = 32.8 SD = 8.7). All participants were female. *N* = 10 participants were identified as having autism from the total sample of *N* = 164 reviewed service user records. A frequency of 6.10% was calculated for the service user population. Of the *N*= 10 participants identified, *N* =1 was excluded due to being in a period of post-surgery recovery. = 9 were invited to participate in Phase Two, *N* = 5 opted in.

*Phase Two: Qualitative Phase*

Four overarching themes were identified through the process of inductive TA of the interview transcripts: Power, Rapport and Communication, Expectations and Uncertainty, and Practicalities. These are outlined with illustrative quotes below. Table 2 provides a summary of all themes, all supporting quotes and associated recommendations.

Table 2 Interview Theme Summary, Supporting Quotes and Service Recommendations (*N*=5)

| Overarching Theme | Subtheme | Supportive Quotes | Recommendations |
|---|---|---|---|
| **Power** | Belief | *"Sometimes people challenge you. Like, just challenging of you and your experience and it's like they don't believe you..." (P2)*<br><br>*"I always feel like I'm not believed or listened to." (P2)*<br><br>*"it kind of feels like it was brushed off. (P3)*<br><br>*"I feel like they made it sound like I was anticipating in the pain, so therefore it wasn't necessarily valid." (P3).*<br><br>*"You have to repeat yourself a lot when you see different people and sometimes you feel like what you are saying is challenged." (P4)*<br><br>*Everyone that I've seen at the for the pelvic pain clinic really listened and took onboard what I said. They have always been really respectful and validating. " (P1)* | *Ensure the MDT communicate to the service user that the pain experiences they have shared are validated, acknowledged and believed. Using clear direct statements which indicate the experience is believed, supported by non-verbal gestures such as nodding, may help communicate this. |
| | Control and Agency | *"I felt myself snapping into a bit of a meltdown myself and I was a bit like I just wanna go." (P1)*<br><br>*"…in a sense I'm kind of stuck in the appointment…" (P1)*<br><br>*"The whole way through the lady said continuously, if you wanna stop, you just say and we will stop. That helped me feel more in control" (P1)*<br><br>*"And she always gives me the option of coming back another time to do it (physical examination)." (P2)*<br><br>*"I was very stressed and they said that I can come back for that (physical examination)." (P2)* | Prior to and during physical examinations communicate that the service user is in control of the assessment. Decide on a way the service user can non-verbally communicate a need to pause or stop the examination prior to commencing examination. State clearly that the service user is the expert of their own experience and body, they are not wrong in stating the way they in which they wish examinations to be carried out.<br>*Remind service users they can end the examination at any time. |

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| | *"Even though I wasn't kind of in control because they were doing it, I felt in control because I knew if I said I can't do this, she would have stopped completely." (P1)*<br><br>*"I felt myself snapping into a bit of a meltdown myself and I was a bit like I just wanna go." (P1)* | |
| | *"She' was like, we're gonna do this now. " (P4)*<br><br>*"they've always given me that option." (P1)*<br><br>*"They haven't said we're doing this, whether you like it or not." (P1)* | Providing a clear step by step summary of what the physical examination entails prior to the examination appointment. This would benefit from information being communicated multimodally. This could include a video walk through. During the examination it could be helpful to give the service user the option to be walked through which step is being carried out and what is next. Where possible provide the service user with choices e.g., breaks or communication preferences. Keep choices to discrete options rather than using open ended questions. |
| | *"I was quite surprised because it is quite a vulnerable situation. I didn't have any time to sort of prepare myself that all these people." (P5)* | Communicate clearly who will be at the MDT, for which parts of the assessment and for what purpose. |
| Advocating | *"I have hidden disabilities…"…"He wears a lanyard to say I care for a person with hidden disabilities which works for us." (P1)*<br>*"I overheard a nurse being not very nice about me saying I've made-up my autism to get my husband to come along to the appointment. I told the Gynaecologist and Psychologist, and they said they would mention it to the staff, cause that's not acceptable. They were quite understanding as I was a bit flustered." (P2)* | *Provide non-verbal support to advocate. Lanyards which state I have hidden disabilities which could be created and made available to collect from the front desk whilst waiting in the waiting-room. The option to do so could be indicated on appointment letters. |
| | *"I find it difficult to kind of say what has been going on. It's hard for me to advocate for myself."(P4)*<br>*"I have really struggled to advocate for myself too." (P3)* | Offer service users the option to access advocates or bring along someone they trust who can communicate for them to their appointment. |

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| **Rapport and Communication** | Difficulty Describing Pain | *"It's really, really hard. I think for everyone, but maybe more for autistics, its hard to say what your pain feels like cause pain so subjective." (P2)*<br><br>*"It's difficult, isn't it? Because the worst pain someone's felt is different for a different people." (P2)*<br><br>*"I find it difficult to kind of say what has been going on." (P4)*<br><br>*"I remember saying that I'm not very good at knowing how to describe, you know, my body awareness isn't great, so I was unsure how to describe it." (P5)*<br><br>*"It can be quite difficult to describe and communicate to others." (P4)*<br><br>*"Yeah, it's just making something that to me seems a bit complex, putting it basically." (P1)* | Provide a laminated print out of key words to describe pain. Provide visual prompts, examples or perhaps even textures. Acknowledge that pain experiences are different and note there is no right/wrong answer. |
| | | *(describing pain) "when I'm feeling overwhelmed, it's even harder." (P3)* | Offer breaks and allow service user to guide the pace when describing their pain. |
| | Communication Style | *"I don't feel like if I explain it to them, I will be judged, or they will be like ohh, that's really weird, we haven't ever heard of something like this before. " (P2)*<br><br>*"They were just very encouraging and yeah, they weren't very judgmental." (P2)*<br><br>*"They put me at ease and relaxed and they were just accepting…" (P2)* | Maintain a non-judgemental tone when enquiring about pain experience. Explicitly stating at the start of an assessment that there is no judgement on the part of the MDT could help clearly communicate this approach. |
| | | *"Maybe answer my question a more as if I was like a child, but not at a patronising tone. Breaking it down a little bit more." (P2)* | |

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| | *"They are able to switch up how they explain things or how to do something if they can see you're not getting it." (P5)* | *Ensure communication style is clear, discrete but not patronising. |
| | *"I find it helpful when the information is exact." (P4)*<br><br>"*"To me it was quite, like to the point, and focused which helped." (P4)* | *Provide focused and exact information where possible. |
| | "*she always tells me exactly what's gonna happen before it happens." (P2)* | Where possible provide clarity around the process of physical examinations. |
| | *"She was really polite and friendly and reassuring and asking if I had any questions and yeah, and listened to me and yeah, didn't interrupt." (P1)* | Allow the service user to communicate at a pace they feel comfortable with. |
| Non-Verbal Communication | *"I always think that diagrams are a lot more helpful than the words." (P1)*<br><br>*...a diagrams and things like that and that that would have been helpful. " (P5)*<br>*"a little diagram and it shows you the pathways that, yeah, that would have been helpful in in a pack… because I'm quite visual, I like to see to understand. (P2)* | *Adopt flexible communication methods and offer diagram representation where possible. |
| | *"I was given leaflets… and I researched all the leaflets, and I read it all up at home which was useful." (Written information) (P1)* | *Provide written information about the MDT ahead of appointment. Use written summaries, diagrams, and visual materials to complement verbal explanations. |
| | *"You could tell that they were genuinely like empathizing with certain situations." (P4)*<br><br>*"She was looking at me and she was giving me her, like, full attention. (P1)* | Ensure non-verbal cues to communicate empathy and attention are used, these include gaze direction towards service user and nodding. Explain at the start that notes will be taken and if a computer will be used state this, so that it is clear when gaze is directed to computer/notes the purpose is understood. |

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| | | *"Everyone kind of made me feel like I was only person going through it at the time."* (P1) | Clearly communicate at the start of the MDT assessment that the service takes a person-centred approach to their care and understands that pain if different for everyone. |
| | | *"I like to write a lot, writing comes much easier to me than speaking. Being able to write in the appointment would have helped." (P3)* | *Offer service user the option to communicate their answers in writing or bring written notes to appointments. |
| | Direct Communication | *"I find it helpful when the information is exact." (P4)*<br>*"To me it was quite, like to the point, and focused which helped." (P4)*<br>"she'll tell me exactly what she wants from me." (P2)<br>*"It was very simple and direct." (P1)*<br>*"Short, direct questions are easier to process." (P3)*<br>*"I felt like a bit more directness would have helped." (P5)* | *Use direct, clear language. |
| **Expectations and Uncertainty** | Expectations | *"They discussed it, so I knew what to expect." (P4) (physical examination)*<br>*"I knew what to expect." (P2) (physical examination)*<br>*"I knew what to expect so it was okay." (physical examination)*<br>*"I had a rough idea…" (physical examination) (P1)* | Information on outline the steps in a physical examination to be provided ahead of appointment. Provide this multimodally. |
| | | *"I didn't really know what to expect going into it which made me feel uneasy. " (MDT ax) (P4)*<br>"*We weren't expecting to be there as long as we were." (P1) (MDT ax)*<br>*(Provide assessment attendants ahead of appointment) "So you know what to expect. That probably would have been helpful". (P2) (MDT ax)* | |

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| | *"I would have really benefitted just from like an overview of what to expect." (P3) (MDT ax)*<br><br>*"I didn't know that it was multidisciplinary before I got there. I arrived and there were like 6 people in the room, which was a bit of a shock for me." (P5) (MDT ax)*<br><br>*"…cause when you go in and sometimes you can be a bit anxious… So when they're like right, well, we're gonna talk about this first, and then we're gonna do this, and then we'll talk about this other area. Then I think it's going to be aright. I'm set to know what this is… I kinda get where we're going with this so I don't feel so anxious anymore." (P1) (MDT ax)*<br><br>*"I suppose maybe a leaflet for like one page could have been like what to expect at the meeting on one page could have been like questions I could possibly encounter at the meeting." (P3) "A page of like what to expect and like who would be in the meeting with you (P3) (MDT ax)*<br><br>*"I think it would have been useful to be told like in advance, not necessarily like specific names, but say like in this meeting you can expect there'll be a representative from these different areas and this is why they're there." (P5) (MDT ax)*<br><br>*"…a lot of times like when I go to an appointment I don't know what to expect. " (P3)* | *Information on the MDT assessment to be provided prior to appointment. This should include timing of the session, who will be present, their role and aims of the session. Some example questions may also be useful. A video walk through could also help. This information could also be printed on a laminate card and given to the service user whilst they sit on the waiting-room. |
| Uncertainty | *"I didn't really understand why all those people were there." (P5) (MDT ax)*<br><br>*"I was just a bit confused because I didn't know they were all gonna be there." (P5) (MDT ax)*<br><br>*"I didn't really know what to expect going into it." (P4) (MD ax "I didn't know that it was multidisciplinary before I got there." (P5) (MDT ax)* | |

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| | | *"I didn't know what was going on and I was kind of sat there, like, was I supposed to do something?" (P5) Physical examination)* | |
| | | *"I didn't really know who to speak to". (P5)* | Contact detail summary with staff photos provided for follow-up queries to be provided after MDT assessment. |
| **Practicalities** | Pacing | *"really long process and by this point, yeah, I was just really frustrated. "(P1) (MDT ax)*<br><br>*"She was really polite and friendly and reassuring and asking if I had any questions and yeah, and listened to me and yeah, didn't interrupt." (P1) (MDT ax)*<br><br>*"We weren't expecting to be there as long as we were." (P1) (MDT ax)*<br><br>*"It didn't drag on." (P4) (MDT ax)*<br><br>*"She wasn't dragging it out." (P1)*<br><br>*"They didn't rush me or anything." (P2)* | Set explicit expectations for timings of appointments and ask service user about their pacing preferences where possible at the outset. Offer the option to pause/break from discussions if helpful. |
| | | *"I was waiting like an hour and a half in the waiting room to be seen." (P1)* | Provide option for service user to wait in car or side room if available and offer call back to waiting-room from reception to avoid service user sitting in potentially overstimulating, busy waiting room. |
| | Comfort/safety | *"I would feel uncomfortable talking about my pain in a more general group." (P5)*<br><br>*"I wouldn't feel comfortable around people talking about other scenarios, and observing people sharing same experiences and whatever. I just don't feel comfortable around people I don't really know." (P4)* | Provide a video walk through of group sessions. Provide more scaffolding/remove anxiety provoking ambiguity. For example, state clear suggested 'rules' for engagement, such as where to sit, turn taking for responses etc. |

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| | *"If they're like group discussion type things, that would probably be overwhelming for me and difficult for me to participate in." (P3)*<br><br>*"I just find the group ones a little bit more uncomfortable." (comfort/group dynamics) (P1)* | |
| | *" I think online works best for me as I probably would rather not be around other people. " (P3) (Online/group dynamics)*<br><br>*"I didn't have to go anywhere and I know where my own stuff is so I feel more comfortable." (P2)*<br>*"where at home I feel a lot more in control. " (P1)*<br><br>*"I felt a lot more happy to chat about things because I'm in my own space." (P1)*<br><br>*"everyone feels more relaxed on their home…" (P1)* | *Offer online sessions where possible. This may be particularly beneficial for group sessions. |
| Online | *"the online appointments we just a lot easier." (P1)*<br><br>*"Online appointments were convenient for me." (P1)*<br><br>*"…for the logistical side of things, the online meetings were easier to attend" (P1)*<br><br>*"this was all on zoom which was better for my mental health state as well. (P2)*<br><br>*"A group physio thing online perhaps or like a sort of support group with people who had similar presentations I think would be useful." (P5)*<br><br>*"Having later appointments via zoom helped. " (P4)* | |
| Sensory sensitivity | *"I was so overwhelmed" (P3)*<br><br>*"Here was quite a lot of noise in the waiting room so I was getting a little bit sensory overloaded." (P1)*<br><br>*"I was getting a little bit sensory overloaded." (P1)* | |

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| | *"I am incredibly hypersensitive to light. " (P3)*<br><br>*"normal lighting for everyone else It really hurts my eyes and it's really overstimulating and t's just another sensory overload." (P3)*<br><br>*"…the strip lighting is like going, and it starts sort of blinking. That drives me insane as well." (P2)*<br><br>*"If you sort of put yourself in the mind of someone that sees things very intensely, smells, sounds, sights and look at a room…" (P2)* | *Assess environmental factors which could be modified such as lighting, sound, and temperature and mitigate risk of sensory overload where possible.<br>Offer remote options where appropriate. Offer use of ear defenders. Offer alternative waiting-room space if available. Offer lights on lower setting (in rooms with this functionality). |
| | *"It was overstimulating but I think a lot of that was because of their amount of people." (P3)* | Where there are additional staff present for learning, given the RUH is a teaching hospital, give service users the option for them to not be present to reduce number of people in the MDT ax. |
| | *"…with attending in person, you've got the whole stressing about getting there and being on time and you know and the environment and whether the environment's OK." (P2)* | Provide a video walk through of spaces including parking area, waiting room and example clinic room with where examination would take place. Make this available on website. |

*Recommendation from service user or utilising service user specific language.

**Theme 1: Power**

The first overarching theme, Power, incorporated three subthemes: Belief, Control/Agency, and Advocating. This theme captured participants' experiences of power and control in relation to healthcare professionals and how their interactions shaped their sense of autonomy and agency. The theme of Power was particularly pertinent in relation to the initial MDT assessment and during physical examinations.

Three participants described occasions when they felt their pain experiences were questioned or dismissed by healthcare professionals; this included interactions which occurred prior to accessing PPS but which had shaped their expectations. These encounters left participants feeling invalidated, frustrated, and undermined the trust/rapport with their healthcare professionals. This was evident when Participant 3 stated:

> *"I feel like they made it sound like I was anticipating the pain, so it therefore wasn't necessarily valid." (P3).*

On the contrary, one participant noted that when their pain experiences were acknowledged this led to feeling respected and validated:

> "*Everyone that I've seen at the pelvic pain clinic really listened and took onboard what I said. They have always been really respectful and validating." (P1)*

All participants referred to their perceived control over their care, particularly during physical examinations. Four participants described situations where clinicians offered choice and transparency around the process for examination, which led to feeling safer and more respected. This was demonstrated when Participant 1 stated:

> *"The whole way through the lady said continuously, if you wanna stop (the physical examination), you just say and we will stop'. That helped me feel more in control" (P1).*

Conversely, two participants described a situation where they felt decisions were imposed or communication felt rushed. Participants reported heightened anxiety or withdrawal in these instances. This was evident when Participant 5 stated:

> *"I was quite surprised because it is quite a vulnerable situation. I didn't have any time to sort of prepare myself for all these people." (P5)*

Self-advocacy was deemed important, with all participants refencing the importance of advocating for themselves. Two participants spoke specifically about the need to advocate for their autism to be known, and three participants acknowledged difficulties in advocating verbally, especially when fatigued or anxious. This was clear when Participant 3 stated:

> *"I have really struggled to advocate for myself too… when I'm feeling overwhelmed, it's even harder." (P3)*

**Theme 2: Rapport and Communication**

The second overarching theme identified was Rapport and Communication. This theme highlighted how the quality of communication (verbal and non-verbal) shaped the overall experience and engagement service users.

All participants described challenges in describing their pain, and two participants directly related their difficulty in describing their pain to autism related factors, such as poor interoceptive awareness. This was clear in the way Participant 2 stated:

> *"I remember saying that I'm not very good at knowing how to describe, you know, my body awareness isn't great, so I was unsure how to describe it." (P5)*

Communication style was mentioned by all participants. Participants consistently valued compassionate and non-judgmental communication with four participants describing how this style of communication made them feel more at ease. This is illustrated by the comment made by Participant 2:

*"They were just very encouraging and yeah, they weren't very judgmental. They didn't make me feel like I was being silly which helped me feel more comfortable." (P2)*

Use of direct language was consistently favoured, with all participants stating a preference for this form of communication. This was illustrated by the comment made by Participant 1:

*"It was very simple and direct which I liked." (P1)*

The part non-verbal communication played in shaping experience and engagement was evident throughout responses of all participants. The value of visual or written aids to enhance understanding (bidirectionally) was expressed by four participants and is demonstrated by Participant 5:

"*... diagrams and things like that would have been helpful."* (P5)

Three participants commented on the impact of non-verbal communication such as gaze direction and eye contact, and facial expressions. There was no consistent preference for form of non-verbal communication, however. One participant expressed a preference for consistent eye contact:

*"When I was talking, she was looking at me and she was giving me her, like, a full attention she it felt like she was very interested in what I was saying." (P1)*

Another participant expressed distress in relation to eye contact:

*"She was sort of two metres that way and I've found that easier because then I haven't got a stress about people being like here and staring at me." (P2)*

**Theme 3: Expectations and Uncertainty**

The third overarching theme, Expectations and Uncertainty, encompassed how participants experienced and managed their expectations for their care and input with the PPS. This was particularly pertinent in regards to the initial MDT assessment.

All participants made reference to what they expected from the initial MDT assessment. Three participants clearly stated that they would have benefited from more information prior to the MDT assessment to manage feelings of uncertainty. This was clear from the comment made by Participant 3:

*"I would have really benefitted just from like an overview of what to expect." (P3)*

Uncertainty around what to expect from appointments negatively impacted on service user experience (resulting in confusion or anxiety), which was expressed by all participants. This was evident by a description provided by Participant 4 in relation to their initial assessment:

*"I didn't really know what to expect going into it which made me feel uneasy." (P4)*

**Theme 4: Practicalities**

The final overarching theme was Practicalities. This theme represents the logistical, and environmental aspects that shaped participants' experiences, this included reference to accessibility, the clinical environment, and pacing.

Three participants emphasised the importance of appointment timings. This was clear from the description provided by Participant 1:

*"it was a really long process and by this point, yeah, I was just really frustrated." (P1)*

All participants indicated that the idea of group sessions evoked discomfort. This was evident in the comment made by Participant 5:

*"I would feel uncomfortable talking about my pain in a more general group." (P5)*

A preference for online appointments was consistent across four participants and acknowledged to make service users feel safer; this was demonstrated when Participant 2 stated:

*"this was all on zoom which was better for my mental health state as well." (P2)*

Three participants reported sensory sensitivities which impacted on engagement. This was evidenced by Participant 3 who stated:

> *"It was overstimulating, but I think a lot of that was because of the amount of people." (P3)*

## Agreed Recommendations

The core recommendations agreed upon with the PPS were:

- To add an item into the proforma for MDT assessment which refers to neurodiversity as a prompt. This is to ensure that presence of neurodiversity is captured in clinical notes.
- Video walk throughs to be created and made accessible on the PPS website for physical examinations, the MDT assessment, and group interventions. The purpose of these videos will be to clearly outline the aims, structure and format of the different aspects of the PPS. The videos will provide clarity and familiarisation for the service users in relation to the settings the various sessions will be held. These videos will aim to help service users prepare for their appointment.
- MDT to ensure communication style is clear and direct, and reflects respect, compassion, non-judgment and with clear acknowledgement of idiosyncratic pain experience.
- MDT will facilitate agency and control for the service users in terms of pacing particularly prior to and during the physical examination.
- MDT to develop and provide suggested 'rules' for engagement for the group interventions.
- MDT to consider options for offering service users alternative places to wait for appointments to reduce sensory overload.

The following action plan was agreed to support the implementation a subset of the above:

- Physiotherapists would lead on the development of the video walk throughs for physical examinations.
- Clinical psychology would lead on the development of the video walk through of the group interventions and develop the rules for engagement.

## Discussion

This project set out to address whether the PPS had an overrepresentation of autistic service users. The audit revealed the PPS has a larger proportion (6.1%) of autistic service users than there are in the general population (1.1%) (NCCMH, 2023). Given the prevalence in the general population reports both male and female prevalence, with a male to female bias, this overrepresentation is particularly striking given the PPS service is a women's only service. Importantly, the result underscored the imperative to consider suitable adaptations to the PPS to improve engagement and experience of their autistic service users (Bultas, McMillin, & Zand, 2016; Cermak et al., 2015).

The project also aimed to explore how the materials/methods of information communication, MDT assessment and group provisions could be optimised for autistic service users. Thematic analysis of service user experiences of aforementioned aspects of PPS service indicated areas of strength as well as areas for improvement, and offered insight into the challenges identified by the PPS MDT in terms of autistic service user engagement and experience.

Analysis revealed key themes around power, communication style, expectations and practical arrangements, which impacted service user accessibility, experience and engagement with the PPS. Participants consistently valued direct verbal communication augmented with opportunity to utilise diagrammatic or written communication, especially for those who found articulating their pain experience difficult. Participant experience was improved with clarity around what to expect from assessment and where control and agency were facilitated by the healthcare professionals. Conversely, when participants experienced sensory overload or perceived a loss of control, trust and engagement was undermined.

Participants expressed a desire to be provided with more detailed information pertaining to their initial MDT assessment prior to the appointment. The clinical environment also impacted on service users' sense of accessibility and willingness to engage.

The overarching themes align with previous research which has indicated communication, sensory considerations and logistical management of care can be barriers to positive autistic patient experience (Nicolaidis et al., 2015; Mason et al., 2019; Weir et al., 2022). Results also reflect the experience of women with CPP who report a protracted journey to diagnosis and describe feeling 'dismissed' (Cox, Henderson, Andersen, Cagliarini, & Ski, 2003). Taken together the results clearly demonstrate the importance of clear, validating, non-dismissive, and flexible communication.

With this in mind, the key recommendations agreed upon with the PPS were to add a prompt regarding neurodiversity to the MDT assessment proforma to ensure it is considered consistently in assessments; to develop video walkthroughs for physical examinations, MDT assessments, and group interventions for the PPS website; communication to direct, respectful, and compassionate; to promote service users' sense of agency and control, particularly around pacing of the physical examinations; to create suggested engagement guidelines for group interventions and to explore alternative waiting areas to help reduce sensory overload.

Overall, the PPS MDT were very receptive to the proposed recommendations and were enthusiastic about implementation. One area that would benefit from further exploration is the group-based interventions. Despite there being a common theme for service users to either express a discomfort in relation to the idea of group-based intervention or a preference for this to be offered online, the MDT reflected that delivering the group content in person provided an important opportunity for peer support; benefits which they did not feel would be fostered if online.

*Limitations*

Several limitations should be acknowledged. Firstly, participation was low, with half of those identified as potential participants ultimately taking part. Although there was

considerable flexibility offered to accommodate service users' needs, including rescheduling, time-flexibility and multiple opportunities to problem solve around availability, there remained a low rate of retention which ultimately limited the overall sample size. As a result, the perspectives captured may not fully represent the full range of experiences within the wider cohort of autistic individuals accessing the pain service. The scheduling difficulties evident for those who did not take part would have been useful to capture in relation to the experience of appointment scheduling and logistics of the PPS.

The audit process relied on information documented in clinical notes. The MDT had expected a higher incidence of service users with autism than were identified in the audit. It is possible that autism diagnosis was not consistently or explicitly recorded in the clinical documentation even when discussed with the MDT. Consequently, not all autistic service users may have been captured in the audit, leading to an underrepresentation of frequency and opportunity to participate. It would also have been of value to interview non-autistic service users. This would enable us to understand if similar themes arose for these service users, if there were themes identified that were specific to autistic service users.

It is important to note that it was beyond the scope of the project to evaluate the impact of the recommendations. The project would be strengthened with follow-up secondary analysis to support more evaluative aspects. This could include a further audit for the subsequent two-year period, and identification of a new sample of autistic service users who could be invited to explore their experience of the aspects of the service that have been modified.

The project would have been strengthened by further inclusion of experts by experience across more aspects of the study. Although a single researcher is sufficient for inductive TA, as long as measures to ensure rigour are adhered to, if I were to complete the study again with more resource, I would consider having an expert by experience as a second researcher who could complete TA analysis in parallel. This could then facilitate co-creation of data interpretation and associated service recommendations.

It could also have been advantageous to have ex-service users, as additional experts, to choose which aspects of the service to explore, contribute to the interview questions asked,

be consulted on the interpretation of the data and recommendations developed, and be involved in the wider dissemination of the results.

See Appendix D for a Lay Summary of the study.

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**Theory Driven Research Project**

# The Impact of Teachers' Awareness of Pupil Autism Diagnosis on Teacher Attribution, Intervention Choice and Expected Behavioural Management Efficacy when working with Repetitive and Restricted Behaviours

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## Abstract

**Background**: Restrictive and Repetitive Behaviours (RRB) are a diagnostic feature of autism that can challenge inclusive practice in school classrooms. RRB can be subdivided into lower order, motor or sensory seeking mannerisms, and higher order, complex and cognitively mediated such as rituals or preference for routine. Little is known about how teachers' understanding of RRB and their management are shaped by factors such as diagnostic awareness.

**Methods**: This study used an online vignette-based design with 192 primary school teachers, randomly assigned to one of four groups which differed in diagnostic awareness and RRB subtype. Teachers selected a management strategy and rated attributional beliefs (locus, controllability, stability) and expected behavioural management (BM) efficacy.

**Results**: Teacher's aware of the autism diagnosis rated RRB as more internally driven, stable, and amenable to effective intervention. Higher order RRB were rated as more controllable and were associated with greater BM efficacy expectations, but only when participants were aware of the autism diagnosis. Collaborative interventions were preferred for higher order RRB regardless of diagnostic awareness, whereas for lower order RRB a collaborative intervention selection was more likely when participants were aware of the autism diagnosis. Teaching experience, diagnostic awareness, and controllability attribution significantly predicted BM efficacy ratings.

**Conclusions**: Findings suggest diagnostic disclosure shapes teachers' attributions of children's agency in RRB, choice of management strategy, and their BM efficacy. It could be helpful for clinicians to share with parents of autistic children the positive impact diagnostic disclosure could have in facilitating collaborative-inclusive engagement in the classroom.

## Background

*Diagnosis Disclosure*

Autism is an 'invisible' condition which requires diagnostic disclosure for those around the individual to be aware of the diagnosis [1]. Unfortunately, fear of stigma and power imbalances can lead to a reluctance to disclose one's own or a child's autism diagnosis to others [2-5].Parents of autistic children may wonder whether diagnostic disclosure will promote understanding and compassion or lead to increased exclusion and stigma [1, 2, 6].

A recent systematic review of vignette-based research revealed that disclosing an autism diagnosis had positive outcomes in adults [2]. Specifically, diagnostic disclosure led to increased positive appraisal and more inclusive behaviour [1, 7-10]. One proposed explanation is that the diagnostic label provides a context and explanation for a particular behaviour that might otherwise be negatively appraised [11]. Interestingly, diagnostic disclosure does not lead to increased inclusive behaviour when participants themselves are autistic [7]. It has been argued that this is because autistic individuals can more easily infer autism in others and are not reliant on disclosure for diagnostic awareness [7].

There is a growing movement promoting diagnostic disclosure throughout the lifespan [5, 6]. Diagnostic disclosure brings about positive change in autistic children whose parents have disclosed their autism diagnosis to them; such that they demonstrate enhanced self-advocacy and insight into their own strengths and weaknesses [6]. Research has also shown that increased communication about autism between teachers and parents leads to improved problem solving and teacher efficacy [12]. Shared diagnostic awareness also supports positive identification with a peer group and psychological wellbeing [13].

*Inclusive Practice*

Legislation around Special Educational Needs and Disability (SEND) provision [14] stipulates that teachers should make 'reasonable adjustments' to their practice to enable children with SEND to 'learn and participate fully in the school community' [15]. The process for facilitating inclusive practice, however, remains a complex and under researched area of education [16, 17].

Factors that can influence inclusive practice include how behaviour is causally appraised and a teacher's perceived efficacy for strategy implementation [18, 19]. Inadequate training and support are cited as barriers to facilitating inclusive practice [20, 21].

*Restricted and Repetitive Behaviours*

Restricted and Repetitive Behaviours (RRB) are a key diagnostic criterion for Autistic Spectrum Disorder (ASD) in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) [22]. The term autism is used as it is more neuroaffirming and tends to be preferred by autistic people [23]. RRB can be subdivided into lower order behaviours and higher order behaviours [24]. Lower order RRB are characterised by motor mannerisms (e.g., hand flapping), repetitive use of objects (e.g. excessive twisting of hair), are often sensory seeking, and have a physiological drive [25]. Higher order behaviours include rituals, strong preference for routine or an intense fascination with a specific topic [26, 27]; and are more complex and cognitively-mediated than lower order RRB [24, 28].

Both forms of RRB are functional, serving as a self-regulatory coping mechanisms during periods of 'overarousal' [24, 29-31]. Despite the functionality, research indicates that RRB are not consistent across the life span - lower order RRB are more likely to present in younger children and often resolve over time, whereas higher order RRB often present in older children and can persist into and throughout adulthood [32, 33]. A link between cognitive abilities and RRB has also been proposed. Lower order RRB are more common in autistic children with lower cognitive and communication abilities, conversely, presentation of mild social communication deficits at a younger age can predict the development of more severe higher order RRB later in development [33].

*Teachers Attribution*

Attitudes of teachers can facilitate or hinder the successful implementation of behavioural management and inclusive practice [31, 34-36]. RRB are time-consuming to manage and can impede learning [31, 33, 37, 38]. Despite this, research into how teachers perceive RRB and the factors that influence beliefs and decisions around RRB management is sparse [31].

Research utilising attribution theory [39] as a framework to examine the interplay between educators and autistic students in the classroom has been fruitful recently [40]. Causal attributions of behaviour influence perceived responsibility, affect, and behavioural responses [41] and are based on three domains: locus, controllability, and stability of the behaviour (Weiner, 1993). Locus refers to whether the cause of the behaviour is internal or external to the individual; internal factors may include aptitude, beliefs or physiological states, and external factors could include aspects of the classroom environment, situational and systemic factors [39]. Controllability refers to the degree in which the behaviour is considered volitional, and stability refers to the likelihood of the behaviour being sustained over time [39].

Teachers' attributional beliefs in the classroom are influenced by several factors. Behaviours directed at others are perceived as more controllable [42], while behaviours displayed by individuals with low cognitive ability are appraised as less controllable [43]. SEND experience results in more external behavioural attributions [44, 45]. Importantly, these attributional beliefs shape emotional response to behaviours and guide practice [18, 44-46]. Internal causal attributions promote teacher efficacy [47] and inclusive, joint engagement strategies are preferred when an autistic behaviour is considered more controllable [43]. Behaviours are considered more amenable to change when appraised as both more internal and more controllable [43].

Teacher attributions of controllability and stability have also been shown to vary for different RRB subtypes [40]. Teachers rated Higher order RRB as less controllable and more stable over time, and lower confidence in management compared with lower order RRB [40]. The authors of this study did note, however, that their results were inconsistent with their hypotheses and acknowledged it would be of value to see if their findings could be replicated [40].

An under-researched factor is how diagnostic awareness shapes attributions and resultant interactions between educators and autistic students. Despite research highlighting the importance of communication between teachers and parents regarding autism [6, 12, 37, 48], there is no specific guidance given to parents on how and when to disclose an autism diagnosis to the teacher or the autistic individual themselves [6, 49].

Expanding on previous research it is plausible that knowledge of an autism diagnosis will affect the attributions, intervention decisions and expected management efficacy of RRB in the classroom. Understanding the interpersonal consequences of diagnostic disclosure in a classroom setting could be crucial for identifying and addressing barriers/facilitators to inclusive and effective teaching practice.

## Aims

The primary aim in this study is to examine whether teachers' diagnostic awareness of autism (aware/unaware) and RRB type (lower/higher order) impacts upon teachers' attribution beliefs, intervention choice, and expected behavioural management (BM) efficacy.

If significant interaction effects of diagnostic awareness and RRB type on BM efficacy are found, a secondary aim in the study is to explore the factors that predict teachers' BM efficacy.

*Hypotheses*

1. There will be a significant main effect of diagnosis awareness on attributional ratings of controllability and locus, such that when autism diagnosis is known RRB will be rated as more controllable and as having more of an internal locus of control.
2. There will be a significant main effect of RRB type on attributional beliefs of controllability and stability, such that higher order RRB will be rated as more controllable and more stable over time than lower order.
3. There will be significant interaction effects of diagnostic awareness and RRB type on attributional rating of controllability and BM efficacy, such that controllability and BM efficacy will be rated the highest in children displaying higher order RRB and when participants are aware of the autism diagnosis.
4. Higher attributional ratings of controllability, presence of diagnostic awareness and higher order RRB will all contribute to an increased likelihood of participants selecting a collaborative-inclusive intervention.

5. Attribution ratings, RRB type and Diagnostic Awareness will predict additional variance in teachers' rating of BM efficacy beyond years of teaching experience, training in autism and participant autism status.

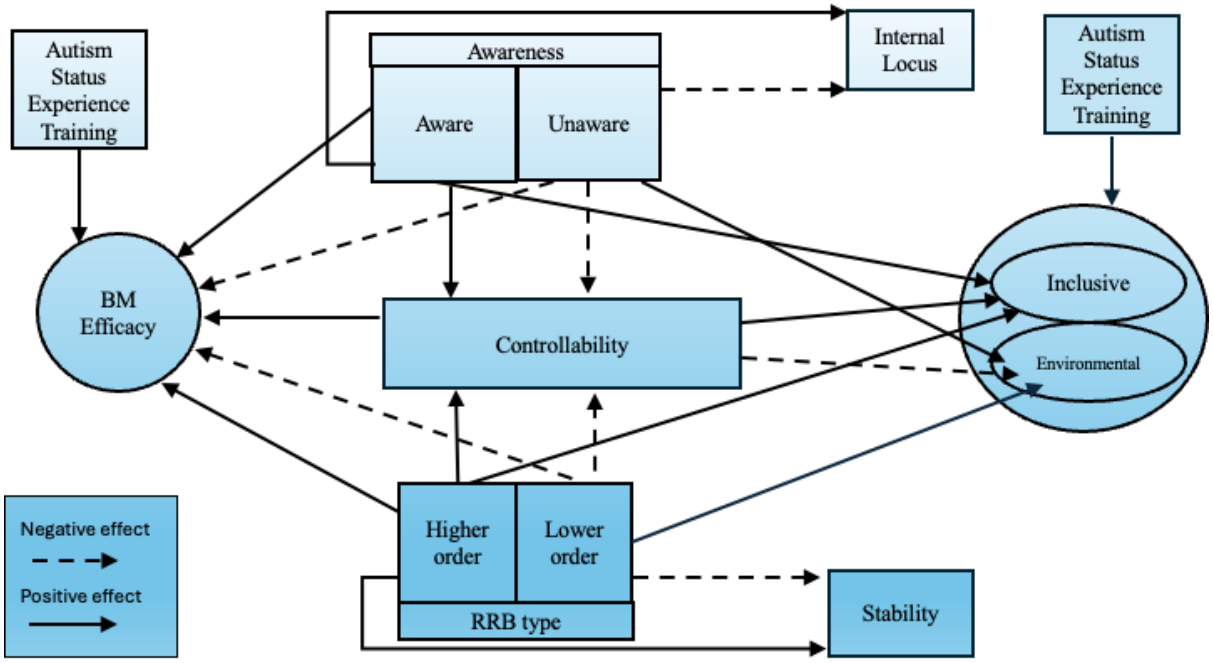


*Figure 1 - Model of Hypotheses*

## Method

*Design*

The study utilised a 2X2 between-participants cross-sectional design, with diagnostic awareness (Aware vs Unaware) and RRB Type (Higher order vs Lower order) as the independent variables.

The study utilised an online vignette-based approach. This allowed for the use of a quasi-experimental design to investigate the impact of diagnosis awareness and RRB type (independent variables) on the attributions (locus, controllability and stability), intervention choice, and expected behavioural management (BM) efficacy reported by teachers (dependent variables).

Control variables included participant autism status [7], having undertaken autism specific training, and years of teaching experience [44]. Training was defined as engaging in

a minimum of one hour of learning outside the remit of the teacher training programme. Autism status was defined by participant self-identification as autistic. Years of teaching experience included experience during teacher training given that teacher training involves direct experience working with children in a classroom setting with behaviours which challenges such as RRB.

*Measures*

**Attribution**

Participants rated the RRB for each dimension of attribution [39]: locus of control, controllability and stability, on a 5-point Likert style response scale from 1-5 [50] (Appendix A).

Study-specific attribution items were informed by previous research which had used study-specific attribution items with teacher populations [40], and were developed with the stakeholder group. It was agreed that the phrasing of the items would remain faithful to attribution theory language to facilitate construct validity, and so as not to introduce any erroneous additional information which could increase the likelihood of demand characteristics.

**Behavioural Management Efficacy**

Behavioural management (BM) efficacy was assessed using one question (Item 3), on a 5-point Likert style response scale from 1-5 [50], adapted from the Teachers Sense of Efficacy Scale [51]. Efficacy in this context pertains to the perceived capacity of the individual to implement what is required to achieve the desired outcome [52] (Appendix A).

**Vignettes**

The vignettes and intervention choices were written in collaboration with a stakeholder group so that the content reflected their experience in the classroom and to increase ecological validity.

The vignettes each outlined a scenario with a child exhibiting a RRB, describing either a higher order RRB behaviour or a lower order RRB. A total of eight vignettes were developed initially. Two vignettes (one higher order RRB and one lower order RRB) were then selected from these eight vignettes based on which two vignettes were deemed most comparable in terms of 'severity' and 'frequency' of behaviour. This decision was made by the stakeholder group.

The final two vignettes underwent validation by 10 Primary School Teachers (independent of the stakeholder group). Vignettes were rated on the degree to which they described the following key dimensions: a behaviour which challenges, a behaviour you might expect from an autistic child, a lower order RRB, a higher order RRB, a collaborative-inclusive intervention and an environmental intervention. See Appendix A for Vignettes. See Appendix B for further detail regarding development of material. See Appendix C for validation tool used.

**Intervention Choice**

Intervention choice was indicated by selecting a collaborative-inclusive or environmental modification intervention. The interventions were described in detail so as not to assume prior knowledge of intervention format (Appendix A).

Although both collaborative-inclusive and environmental interventions have value, and suitability can be seen as context specific, inclusive approaches are more consistent with current policy and guidance frameworks [15].

**Autism Training**

To assess whether the participants had undergone any autism specific training as part of, or in addition to, their teacher training course, participants were asked two questions, see Appendix A

*Stakeholder Involvement*

The research proposal was developed with the input of primary school teachers, and a Learning Support Assistant (LSA), who formed a stakeholder group. The stakeholder group

provided consultation on the design and development of materials, pertinent ethical issues, and was sought after the initial topic of RRB, autism, and diagnostic awareness had been chosen. See Appendix B for vignette/intervention design process.

*Ethical Considerations*

The research was reviewed by, and received favourable opinion from, a subcommittee of the University of Oxford Central University Research Ethics Committee (MS IDREC 1873581). See Appendix D and E.

The study design necessitated some participant deception, as participants were not told the aim of the study in full prior to participating. Deception was as minimal as possible, with just specific reference to autism and RRB withheld from the participants initially. Following completion of the study, participants were provided with a full debrief page which included a clear description of the deception and why this was necessary; and information for the participants to decide whether they agreed for their data to be used for the research or whether they wanted to withdraw their study data and consent. Participants were also provided with contact details for the principal investigator to communicate any concerns or complaints.

*Recruitment*

Recruitment of teachers was facilitated through public sector contact databases, convenience sampling, and snowball sampling methods such as University of Oxford course staff emails.

*Participants*

Inclusion:

- Adult (over 18-years old)
- A Primary school teacher for whom *one* of the below statements applies:

1. Currently working in a mainstream school in England with pupils aged 5-11 years of age.

2. Completed teacher training in the UK within the last 12 months, and as part of that training have worked in a mainstream school in England with pupils aged 5-11 years.
3. Worked as a primary school teacher in a mainstream primary school in England with pupils aged 5-11 years within the last 12 months.

Exclusion:

- Primary school teachers who have trained outside of the United Kingdom.
- Primary school teachers who have not worked at a mainstream school, working with pupils between the ages of 5-11 years old in England within the last 12 months.

The required sample size was $N = 192$, based on a power analysis for MANCOVA completed using G*Power [53] indicating at least $N = 180$ required to achieve at least 80% power with the reported medium effect size for a significant interaction in teachers' attributional ratings between higher and lower RRB [40].

*Procedure*

Participants were provided with an online Qualtrics Study link with Participant Information sheet (PIS) with incorporated indication of consent (Appendix F). Having read through the PIS and indicating consent, participants were presented with a vignette which described the RRB scenario. Two groups were presented with a higher order RRB and for two groups, a lower order RRB. For two groups the autistic diagnostic label was given as part of the vignette description, for the other two groups no diagnostic label was not given. Participants were randomly assigned to the group, and participants did not know that they had been assigned to a specific group.

Participants read through the vignette at their own pace and were prompted to write a brief summary of their interpretation and how they might intervene. Participants then rated the RRB in terms of Locus, Controllability and Stability. They then selected from two proposed intervention strategies and rated the efficacy. Participants then completed a brief demographics questionnaire noting years of teaching experience, whether they have undertaken any autism specific training, if they identified as autistic, their gender identity, age, and level of education. Participants were thanked for participation and shown a debrief

page which contained all information that was withheld for the purposes of the study. Participants were given the option to close they survey without submitting answers or to submit their answers. All responses were collected anonymously.

*Analyses*

A 2X2 between subjects MANCOVA was used to assess for main effects of diagnostic awareness (awareness vs no awareness) and RRB (lower order vs higher order) on dependent variables, alongside the identification of any interaction effects. Years teaching experience, rater autism diagnosis and autism training were used as covariates [7, 44, 45]. See Appendix G for the data management plan and assumption testing.

Univariate tests for between-subject effects were used to examine the individual effects alongside the identification of any interaction effects. This was followed by completion of pairwise comparisons where significant between-subject effects were identified.

A binary logistic regression was conducted to explore the predictive power of diagnostic awareness, RRB type, attribution ratings, years teaching experience, rater autism status, autism training, and the interacting effect of diagnostic awareness and RRB type on intervention choice.

To examine predictors of BM efficacy, a three-step hierarchical regression was undertaken. In step one, control variables—rater autism status, autism-specific training, and years of teaching experience—were entered. In Step 2, RRB type (Lower Order vs Higher Order) and diagnostic awareness (Aware vs Unaware) were entered. In Step 3, attribution variables—Locus, Consistency, and Controllability—were entered.

## Results

The sample comprised of $N$ =192 primary school teachers. See Table 2 for summary of participant demographics.

Table 1 - Demographics Summary (N =192)

| | Total Sample |
|---|---|
| Age (Years) | 22-62 (M= 38 SD = 10) |
| Gender (Male/Female/Other not specified/ Prefer not to say) | 95:84:8:4 |
| Ethnicity: | |
| White | 138 |
| Mixed or Multiple Ethnics group | 21 |
| Asian, Asian Scottish or Asian British | 17 |
| African | 9 |
| Caribbean or Black | 3 |
| Other Ethics Group | 1 |
| Prefer not to say | 2 |
| Autistic Status (No/Yes) | 180:23 |

Multivariate tests revealed a significant main effect of diagnostic awareness on the dependent variables $F(5, 192) = 6.53$, Pillai's Trace = .15, partial $\eta^2 = .15$, $p < .001$, RRB type $F(5, 192) = 6.93$, Pillai's Trace = .16, partial $\eta^2 = .16$, $p < .001$ and a significant interaction effect $F(5, 192) = 2.51$, Pillai's Trace = .07, partial $\eta^2 = .07$, $p = .032$ , see Table 2 for main effects and interactions.

Table 2 - Main Effects of Diagnostic Awareness and RRB Type, and Interaction Effects Summary (N=192)

| | Diagnostic Awareness | | RRB Type | | | Awareness X RRB Type Interaction Effect |
|---|---|---|---|---|---|---|
| | Mean (SD) | Main Effect | Lower Order Mean (SD) | Higher Order Mean (SD) | Main Effect | |
| Locus | | | | | | $F = 0.22$, $p = .642$ |
| *Unaware* | 2.87 (1.22) | | 3.06 (1.16) | 2.68 (1.27) | | |
| *Aware* | 3.42 (1.12) | $F = 12.09$, ***p<.001*** | 3.69 (1.10) | 3.17 (1.08) | | |
| Total Mean (SD) | | | 3.37 (1.17) | 2.92 (1.20) | $F = 6.87$, **$p = .010$** | |
| Controllability | | | | | | $F = 4.04$, **$p = .046$** |
| *Unaware* | 3.21 (1.24) | | 3.15 (1.29) | 3.28 (1.20) | | |
| *Aware* | 3.15 (1.22) | $F = 0.03$, $p = .860$ | 2.71 (1.24) | 3.56 (1.05) | | |
| Total Mean (SD) | | | 2.94 (1.28) | 3.42 (1.13) | $F = 7.44$, **$p = .007$** | |
| Consistency | | | | | | $F = 0.06$, $p = .804$ |
| *Unaware* | 2.67 (1.21) | | 2.92 (1.09) | 2.44 (1.28) | | |
| *Aware* | 3.17 (1.24) | $F = 8.95$, **$p = .003$** | 3.44 (1.22) | 2.92 (1.22) | | |
| *Total Mean (SD)* | | | 3.14 (1.20) | 2.67 (1.27) | $F = 7.79$, **$p = .006$** | |
| BM Efficacy | | | | | | $F = 5.13$, **$p = .025$** |
| *Unaware* | 3.00 (1.14) | | 3.02 (1.18) | 2.98 (1.12) | | |
| *Aware* | 3.45 (1.15) | $F = 4.91$, **$p = .028$** | 3.13 (1.14) | 3.75 (1.08) | | |
| Total Mean (SD) | | | 3.08 (1.15) | 3.36 (1.16) | $F = 4.35$, **$p = .039$** | |

Significant effects are indicated in bold. Higher scores in Locus indicate more internal attribution. Higher scores in Controllability indicate the behaviour is more controllable by the child. Higher Scores in Consistency indicate the behaviour is more consistent over time. Higher scores in BM Efficacy indicate greater expectation for successful behavioural management.

**Hypothesis 1:**

*There will be a significant main effect of diagnosis awareness on attributional ratings of controllability and locus, such that when autism diagnosis is known RRB will be rated as more controllable and as having more of an internal locus of control*

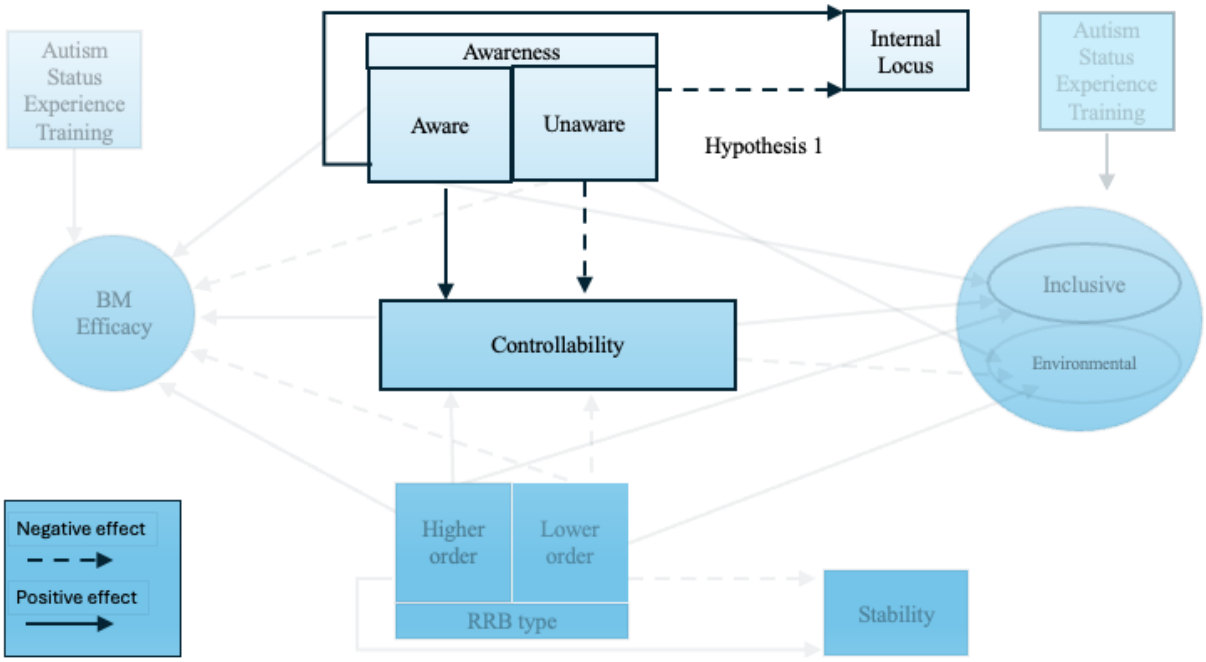


*Figure 2 - Hypothesis 1 Model*

Univariate tests for between-subject effects indicated that diagnostic awareness significantly impacts on attributions of locus $F(1, 188) = 12.09$, $p < .001$, $\eta 2 = .05$, power = .85, and consistency $F(1, 188) = 8.95$, $p = .003$, $\eta 2 = .05$, power = .85, but not controllability. Pairwise comparisons revealed that RRB were rated as more internal (Aware M = 3.42, SD = 1.12; Unaware M = 2.87 SD =1.22, $p < .001$) when participants were aware of autism diagnostic compared to when participants were unaware.

**Hypothesis 2**

*There will be a significant main effect of RRB type on attributional beliefs of controllability and stability, such that higher order RRB will be rated as more controllable and more stable over time than lower order.*

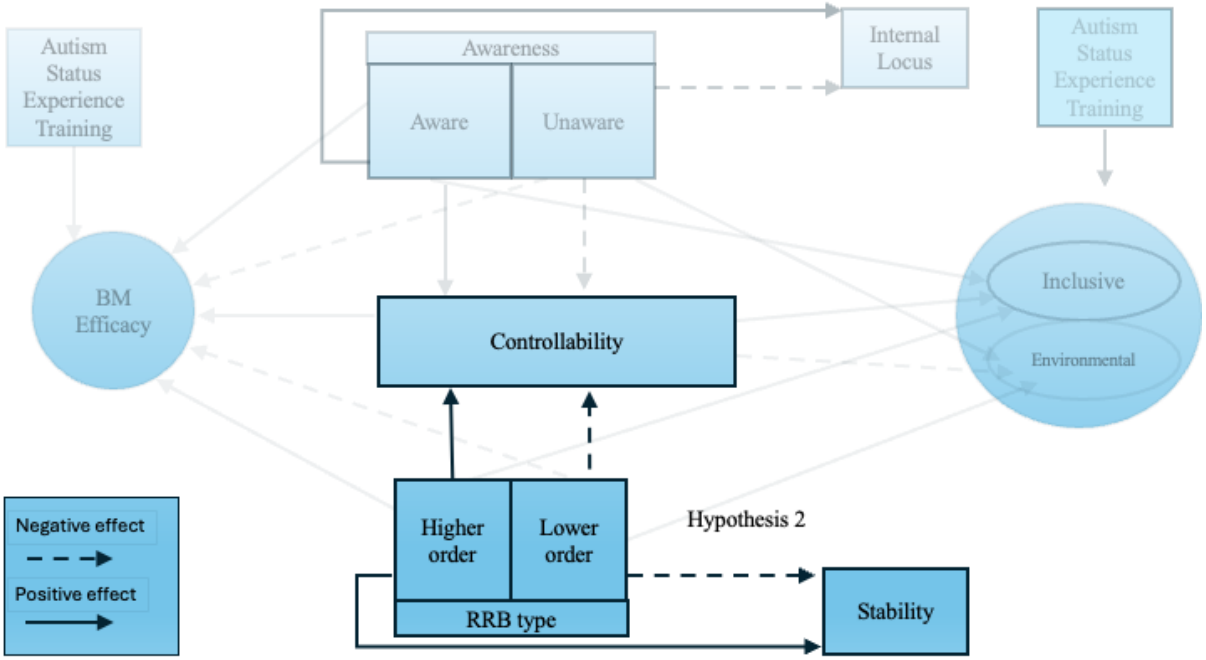


*Figure 3 - Hypothesis 2 Model*

Univariate tests for between-subject effects indicated that RRB type significantly affects attributions of controllability $F(1, 188) = 7.44$, $p = .007$, $\eta 2 = .04$, power = 0.77), and stability $F(1, 188) = 7.79$, $p = .002$, $\eta 2 = .04$, power = .79). Pairwise comparisons revealed that higher order RRB more controllable (Higher RRB M = 3.41 SD = 1.13; Lower RRB M = 2.94 SD = 1.28, $p = .007$) and less stable (Higher RRB M = 2.67 SD = 1.27; Lower RRB M = 3.17 SD = 1.18, $p = .007$) than lower order RRB.

**Hypothesis 3**

*There will be significant interaction effects of diagnostic awareness and RRB type on attributional rating of controllability and BM efficacy, such that controllability and BM efficacy will be rated the highest in children displaying higher order RRB and when participants are aware of the autism diagnosis.*

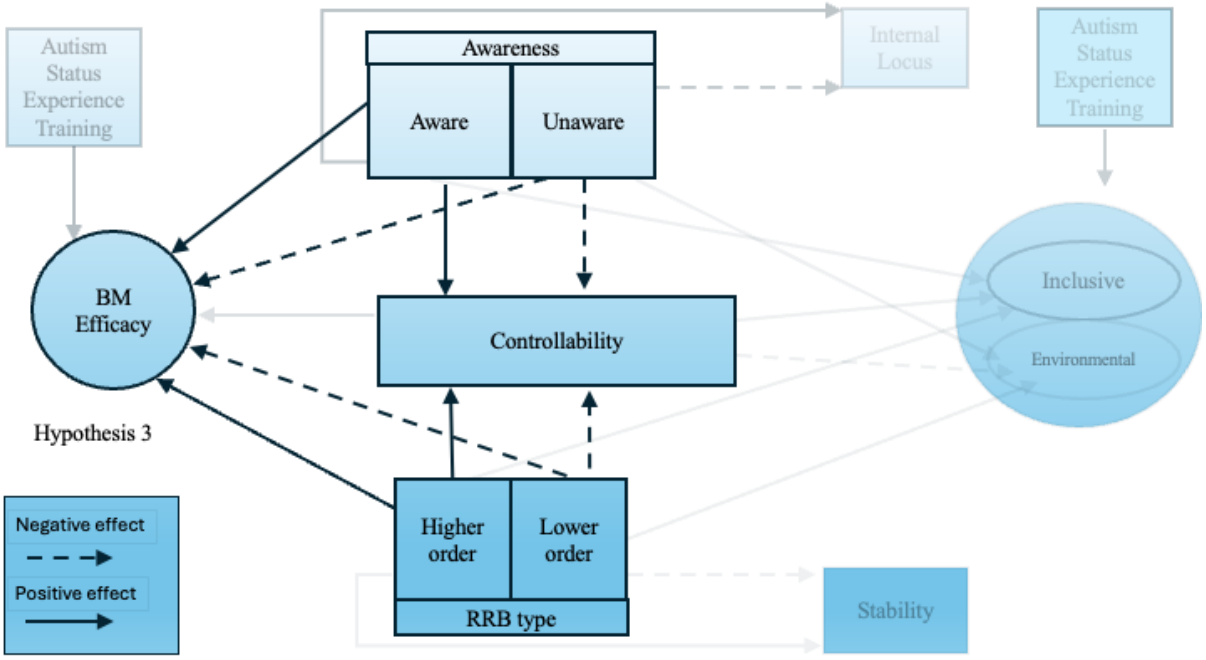


*Figure 4- Hypothesis 3 Model*

A significant interaction was observed between diagnostic awareness and RRB type for the attribution of controllability $F(1,188) = 4.04$, $p = .046$, $\eta 2 = .02$, power = .52).

Pairwise comparisons revealed no significant difference in controllability rating between higher and lower RRB when there was no awareness of diagnosis (Unaware/Higher RRB M = 3.28, SD = 1.20; Unaware/Lower RRB M = 3.15, SD = 1.29, $p$=.610), but with awareness of diagnosis, higher order RRB were rated as more controllable than lower order RRB (Aware/Higher RRB M = 3.56, SD = 1.05; Aware/Lower RRB M = 2.71, SD = 1.24, $p$=.001). However, pairwise comparisons between Unaware/Aware for each type of RRB showed that diagnostic awareness was not associated with any significant difference in controllability rating for lower order RRB (Unaware/Lower RRB M = 3.15, SD = 1.29, Aware/Lower RRB M = 2.71, SD = 1.24, $p$ =. 134) or higher order RRB (Unaware/Higher RRB M = 3.28, SD = 1.20, Aware/Higher RRB M = 3.56, SD = 1.05, $p$ = .190), see Figure 5.

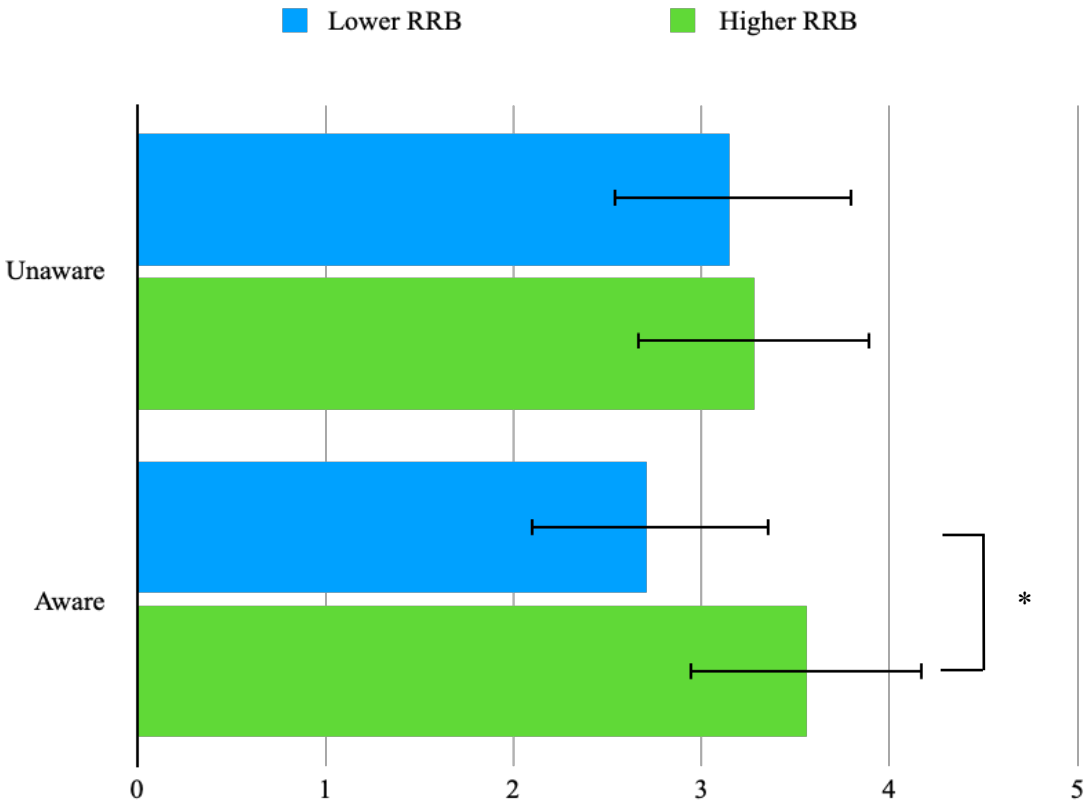


*Figure 5- Controllability rating split by RRB type and Diagnostic Awareness (N=192) * indicates significant difference*

A significant interaction was observed between diagnostic awareness and RRB type for BM efficacy rating $F(1, 188) = 5.13$, $p = .025$, $\eta 2 = .03$, power = .62). Pairwise comparisons revealed that diagnostic awareness did not lead to any significant difference in BM efficacy rating for lower order RRB (Aware/Lower RRB M = 3.13, SD = 1.14; Unaware/Lower M = 3.02, SD = 1.78, $p = .860$) but for higher order RRB, diagnostic awareness led to higher BM efficacy ratings (Aware/Higher RRB M = 3.75, SD = 1.08; Unaware/Higher RRB M = 2.98, SD = 1.12, $p = .028$) (Figure 6).

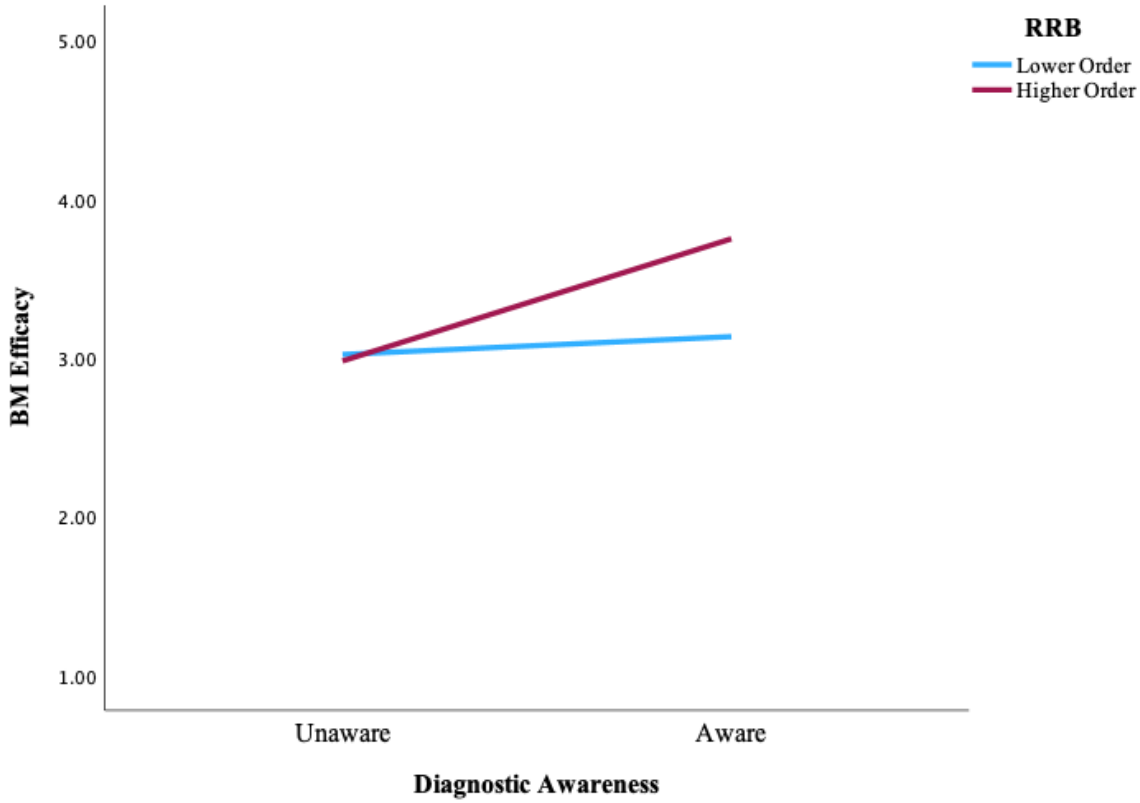


*Figure 6 - Interaction effect for impact of RRB type and Diagnostic Awareness on BM Efficacy (N=192)*

**Hypothesis 4**

*Higher attributional ratings of controllability, presence of diagnostic awareness and higher order RRB will all contribute to an increased likelihood of participants selecting a collaborative-inclusive intervention.*

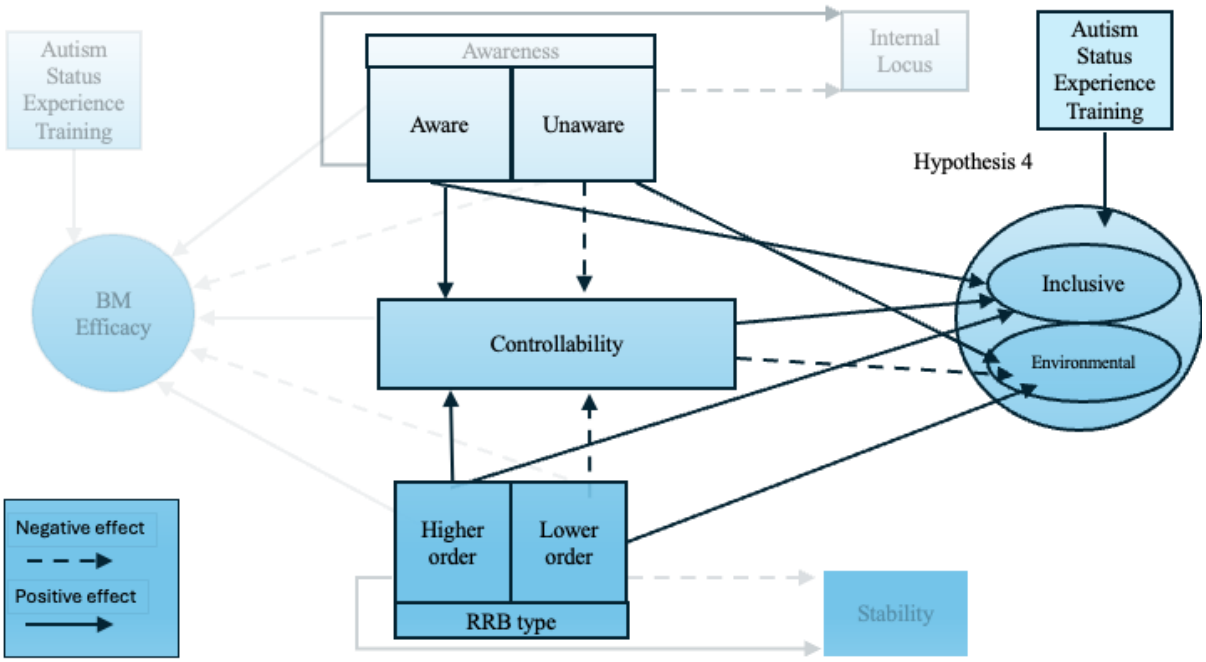


*Figure 7- Hypothesis 4 Model*

A Binary Logistic Regression analysis revealed a significant model, ($\chi^2(7) = 22.24$, $p$ =.002), distinguishing between collaborative-inclusive and environmental modification intervention selection, explaining between 11% (Cox & Snell $R^2$) to 15% (Nagelkerke $R^2$) of the variance, and correctly predicted outcomes for 65.1% of all cases. The Hosmer and Lemeshow test suggested a good fit to the data, $\chi^2$ (8) = 2.20, $p$ =.974 (Table 3).

RRB type significantly predicted intervention choice, β = −1.48, SE = 0.46, Wald $\chi^2$ = 10.33, $p$ = .001, OR = 0.23, 95% *CI* [0.09, 0.56]. For lower order RRB there was a 50% probability of selecting a collaborative-inclusive intervention. For a higher order RRB there was an 82% probability of selecting a collaborative-inclusive intervention. Diagnostic Awareness was also a significant predictor of intervention choice, β = −1.16, SE = 0.48, Wald $\chi^2$ = 5.74, $p$ = .017, OR = 0.32, 95% *CI* [0.12, 0.81]. Participants were 68% less likely to choose environmental interventions than when participants were unaware of the autism diagnosis. Participant autism status also significantly predicted intervention choice, β = −2.06, SE = 0.86, Wald $\chi^2$ = 5.76, $p$ = .016, OR = 0.13, 95% *CI* [0.02, 0.69]. Participants who identified as autistic were 87% less likely to choose environmental interventions than

participants who did not identify as autistic. The RRB by Diagnostic Awareness interaction was also a significant predictor of intervention choice, β = 1.30, SE = 0.64, Wald $\chi^2$ = 4.20, p = .04, OR = 3.67, 95% *CI* [1.06, 12.69]. For higher order RRB the likelihood of choosing a collaborative-inclusive intervention was 81.5% when participants were unaware of autism diagnosis and 79% with diagnostic awareness. For lower order RRB the likelihood of selecting a collaborative-inclusive intervention was 50% when participants were unaware of autism and 76% with diagnostic awareness.

Table 3 - Binary Logical Regression Summary for predictors of Intervention Choice N =192

| Predictor | Intervention Choice | | | |
|---|---|---|---|---|
| | β | *p* value | Wald $\chi^2$ | Exp(β) |
| Autism status | -2.06 | **.016** | 5.76 | 0.13 |
| Experience | -0.19 | .225 | 1.47 | 0.83 |
| Training 1 | 0.74 | .140 | 2.18 | 2.10 |
| Training 2 | -0.46 | .306 | 1.05 | 0.63 |
| Controllability | 0.08 | .558 | 0.34 | 1.08 |
| Locus | 0.05 | .712 | 0.14 | 1.05 |
| Stability | -0.14 | .301 | 1.07 | -.87 |
| RRB | -1.48 | **.001** | 10.33 | 0.23 |
| Diagnostic Awareness | -1.16 | **.017** | 5.74 | 0.32 |
| Diagnostic Awareness * RRB | 1.30 | **.040** | 4.20 | 3.66 |

**Hypothesis 5**

*Attribution ratings, RRB type and Diagnostic Awareness will predict additional variance in teachers' rating of BM efficacy beyond years of teaching experience, training in autism and participant autism status.*

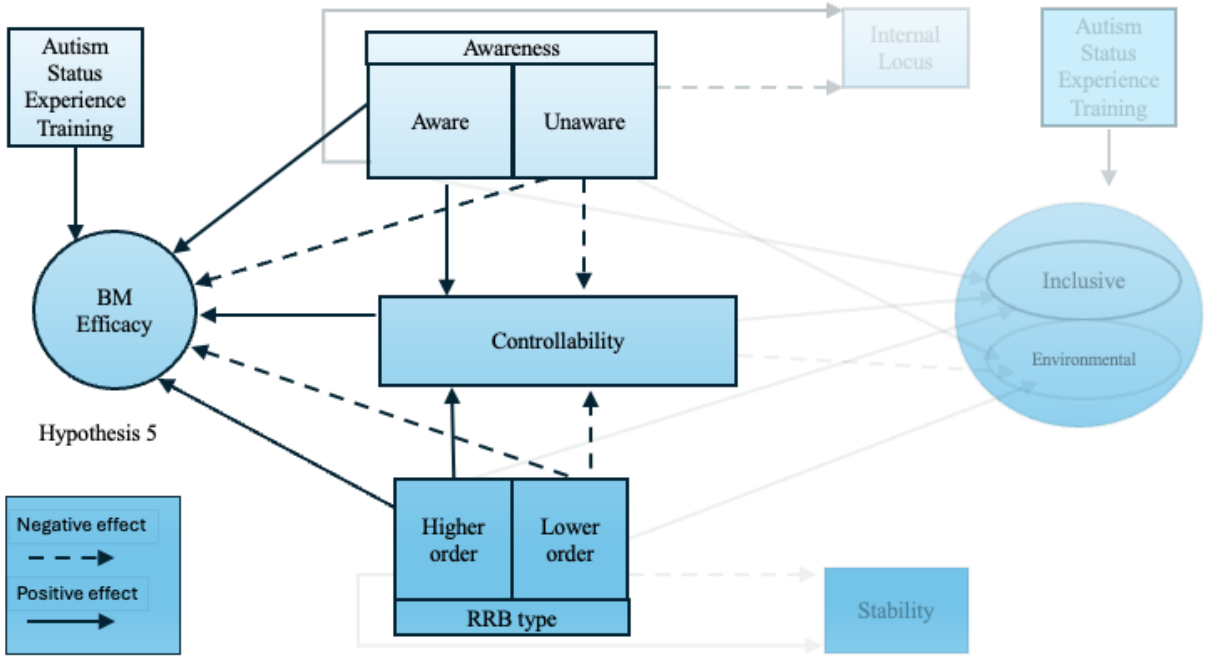


*Figure 8 - Hypothesis 5 Model*

Step 1 of the hierarchical regression was statistically significant and accounted for 10% of the variance in efficacy rating ($R^2$ = .100, $F$(4, 186) = 5.18, $p$ <.001). Within this model years of teaching experience emerged as a significant predictor (β = .338, $p$.<.001), suggesting more experienced teachers tended to rate their BM efficacy higher.

Step 2 significantly improved the model and accounted for an additional 4.3 % of the variance (Δ $R^2$ = .043, $p$ =.011). The overall model explained 14% of the variance ($R^2$ = .144, $F$(6, 184) = 5.15, $p$ <.001) Within this model, teaching experience remained a significant predictor (β = .336, $p$ <.001), diagnostic awareness was also a significant predictor (β = .371, $p$ = .023). RRB type was also a significant predictor (β = .320, $p$ = .046).

Step 3 significantly improved the model and accounted for an additional 5.4 % of the variance (Δ $R^2$ = .054, $p$ =.008). The overall model accounted for 19.7% of the variance ($R^2$= .197, $F$(9, 181) = 4.94, $p$ <.001) and had a medium effect size ($f^2$ =.25). Within this step, teaching experience remained a significant predictor (β = .344, $p$ <.001), as did diagnostic

awareness (β = .478, *p* = .005). Attribution of controllability (β = .207, *p* =.002) emerged as a significant predictor and consistency approached statistical significance as a predictor (β = -.130, *p* = .051). Notably, RRB type was no longer a significant predictor (predictor β = .135, *p* = .421) once the attributional dimensions were included in the model. See Table 4 for summary.

Table 4 - Regression Summary for predictors of Behavioural Management (BM) efficacy N =192

| Predictor | BM Efficacy | | | | |
|---|---|---|---|---|---|
| | β | *p* value | $R^2$ | Δ $R^2$ | *F*-change |
| **Model 1** | | | .100 | .106 | **5.18** |
| Autism status | -.261 | .434 | | | |
| Experience | .338 | **<.001** | | | |
| Training 1 | -055 | .831 | | | |
| Training 2 | .345 | .122 | | | |
| **Model 2** | | | .144 | .043 | **4.66** |
| Autism status | -.140 | .671 | | | |
| Experience | .336 | **<.001** | | | |
| Training 1 | -.057 | .821 | | | |
| Training 2 | .268 | .228 | | | |
| Diagnostic Awareness | .371 | **.023** | | | |
| RRB type | .320 | **.046** | | | |
| **Model 3** | | | .197 | .054 | **4.03** |
| Autistic Status | -.065 | .839 | | | |
| Experience | .344 | **<.001** | | | |
| Training 1 | -.085 | .728 | | | |
| Training 2 | .316 | .150 | | | |
| Diagnostic Awareness | .478 | **.005** | | | |
| RRB type | .135 | .421 | | | |
| Locus | -.058 | .398 | | | |
| Consistency | -.130 | .051 | | | |
| Controllability | .207 | **.002** | | | |

Significant effects are indicated in bold.

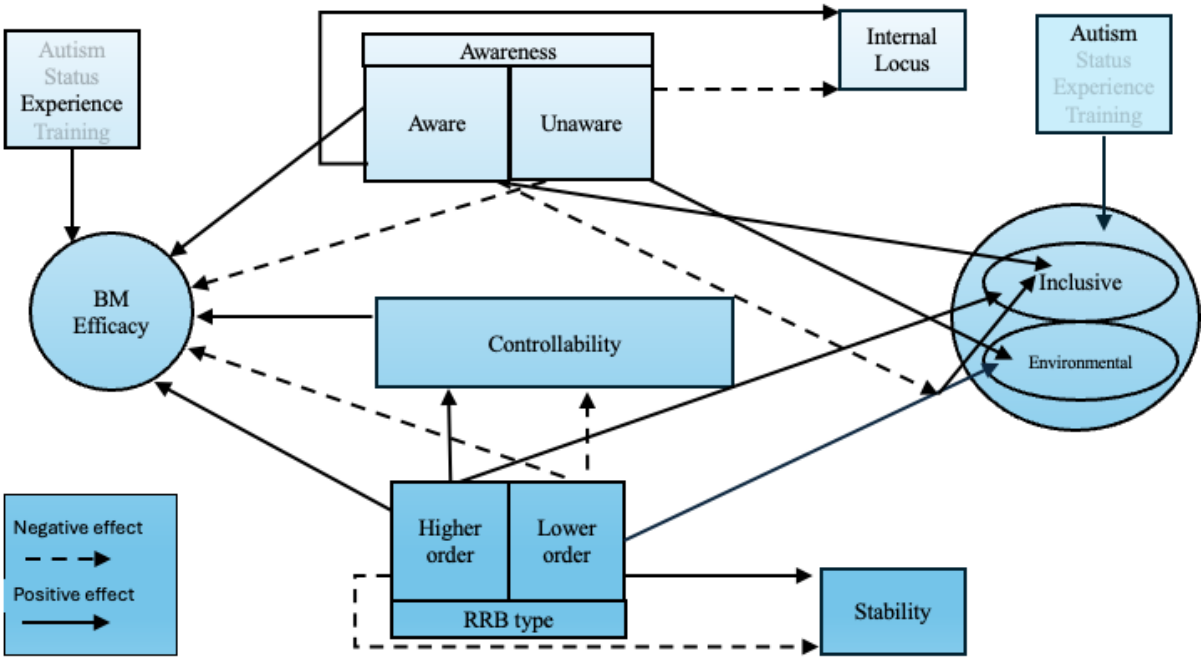


*Figure 9 - Model for Results Summary*

## Discussion

The primary aim of the study was to examine the impact that diagnostic awareness of autism and RRB type had on teachers' attribution beliefs, intervention choice, and behavioural management (BM) efficacy utilising an attribution theory framework [39]. See Figure 9 for a summary of results.

In line with the hypotheses and previous research, RRB type impacted teacher attributions. Teachers appraised higher order RRB as more controllable than lower order RRB [24, 26, 42, 43]. Contrary to the hypothesis, and developmental literature which suggests that lower order RRB often resolve over time [24, 33], lower order RRB were rated as more stable over time than higher order RRB [24, 33].

Results provide partial support for previous research and the hypotheses regarding diagnostic awareness impact on attributions. RRB were rated as more internally driven when participants were aware of the autism diagnosis [12, 24]. Diagnostic awareness did not however, lead to increased controllability rating for combined RRB type as had had been predicted.

Results provided partial support for hypotheses for the interacting impact of RRB type and diagnostic awareness. There was no significant difference in controllability rating between higher and lower RRB when there was no awareness of autism diagnosis but with awareness of autism diagnosis, higher order RRB were rated as more controllable. Comparisons for each type of RRB showed that diagnostic awareness was not associated with any significant difference in controllability rating for lower order RRB or higher order RRB. Diagnostic awareness was shown to exert a stronger and more impactful effect on intervention choice for lower order RRB. For higher order RRB collaborative-inclusive interventions were preferred regardless of diagnostic awareness, for lower order RRB a collaborative-inclusive intervention selection was more likely when participants were aware of the autism diagnosis. One possible explanation, drawing on previous research linking cognitive abilities with intervention approaches [43], is that without diagnostic awareness, lower order RRB were interpreted as signs of poor cognition. However, with diagnostic awareness, these behaviours can be understood as coping mechanisms, which no longer negatively influences perceptions of cognitive ability. This reframing encouraged participants to view collaborative interventions as more appropriate.

The effect of diagnostic awareness on BM efficacy was shown to be selectively driven by the effect on higher order RRB, where diagnostic awareness led to higher BM efficacy ratings. Finally, although overall higher order RRB were rated as more controllable than lower order RRB this effect was shown to be selectively driven by the presence of diagnostic disclosure, with higher order RRB only rated as more controllable than lower order RRB when participants were aware of the autism diagnosis. Controllability was not shown to be a significant predictor for intervention choice as had been predicted.

Secondary analysis complemented the above findings by identifying predictors for teachers' perceived BM efficacy. Experience, diagnostic awareness and RRB emerged as significant predictors. Importantly, however, when attribution beliefs were also included in the model, controllability emerged as a significant predictor over and above diagnostic awareness and experience and RRB type was no longer a significant predictor. This suggests the influence of RRB type on a teacher's perceived BM efficacy is medicated by perceived controllability of the RRB.

Taken together, these results support and build upon, previous research which shows that diagnostic disclosure results in more positive appraisal of behaviour [1, 7-9] and that communication about autism increases teacher efficacy to respond to behaviour [12]. Results provide support for the notion that the diagnostic label provides a context and explanation for a behaviour [11] and that teachers are more confident in BM when a behaviour is deemed internal but controllable [43]. Interestingly, although attributions of controllability were shown to impact perceived BM efficacy, this attribution did not drive intervention choice.

*Clinical Implications*

The findings support the movement for the empowerment of autistic individuals in diagnostic disclosure [5, 6] and highlight the potential value diagnostic disclosure could have in shaping teacher beliefs, responses and perceived BM efficacy when supporting autistic children who display to RRB.

The results suggest that it could be advantageous for clinicians to share with parents, and autistic charities, the positive impact that diagnostic disclosure could have in facilitating inclusive engagement in the classroom. This seems particularly important when managing lower order RRB, as diagnostic awareness was shown to shift intervention choice away from environmental modifications to collaborative intervention strategies. This would be in keeping with legislation around SEND provision [14] which strongly endorses inclusive practice [15]. These results highlight the impact wait-time for autism assessments could have on behavioural management. Children and young people wait an average of 525 days for assessment [54] and in this time the results suggest behaviours may be more negatively appraised and less inclusively managed.

Given that teachers cite inadequate training and support as a barrier to inclusive education for SEND students [20, 21], it would seem important for teachers to receive reflective training on attributional beliefs and how they can be shaped by diagnostic awareness and behaviour type and unconscious bias.

*Limitations and Future Research*

Several limitations should be acknowledged. Classroom-based vignettes cannot capture the complexity of real classroom dynamics, limiting their ecological validity. Future studies could explore whether the findings are replicated with video vignettes, virtual reality (VR), or simulated classroom situations, which may elicit more naturalistic responses. It is important to note however, that videos/VR would also introduce additional variables (e.g., visible child characteristics), which were intentionally minimised in this study. Studies utilising a video/VR could also examine the role of demographics, such as ethnicity and gender, in behavioural attributions, intervention approach and perceived BM efficacy, which would provide a valuable extension of the current findings.

Participants were restricted to forced-choice intervention options and therefore the chosen intervention may not reflect teachers' real-world practices. Future work incorporating qualitative interviews or open-ended responses could provide richer insights in intervention strategies chosen and employed.

It was beyond the scope of the study to account for school context (e.g., mainstream vs. special education), despite evidence this influences confidence and RRB attribution ratings [40]. The predictive model for BM efficacy explained only a moderate degree of variability, suggesting that other important factors remain unexamined. School context may have been a key factor and future research investigating the variance contributed by this variable would be beneficial.

An additional limitation concerns interpretation of stability. Contrary to our hypothesis and research in RRB developmental trajectory [33], lower order RRB were rated as more stable than higher order RRB. One possible interpretation is that participants judged stability over the course of the incident rather than across development. This may explain why higher order RRB were perceived as less stable yet also rated as more controllable and manageable. Clarifying timeframes for stability judgments in future studies would address this issue.

It is also important to acknowledge the limitation of assessing attributional beliefs using study-specific Likert-scale items opposed to a validated attribution measure as this

limits the internalised validity. Although the items were theoretically grounded in the established attribution theory and were developed to reflect the key dimensions of locus, controllability, and stability, with the input of a stakeholder group they did not undergo formal psychometric validation. It is therefore possible that there could have been individual differences in the interpretation of what participants were being asked to rate. This is more likely to be a potential issue for the measure of locus given this construct is more abstract in nature. Caution should therefore be taken when interoperating the result regarding locus attribution, specifically. Future research would benefit the inclusion of an additional measure of external attribution (the opposing attribution to internal locus) as this would have allowed for analysis of consistency across ratings which would strengthen interpretations.

Autism status, included as a covariate, given prior evidence indicated autistic individuals more easily infer autism in others [7], yielded an unexpected finding. Autism status predicted intervention choice, such that autistic participants were more likely to choose an inclusive intervention. It is important to note however, that the proportion of autistic participants (12%) was too small for a direct analysis of group differences. Future research with larger autistic participant samples could provide important insights into the impact of teacher diagnosis on preferred intervention approaches.

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## Executive Summary
## Theory Driven Project

### Context

Autism is an 'invisible' condition which means that those around the individual do not know the person is autistic unless the diagnosis is explicitly disclosed. Unfortunately, fear of stigma and power imbalances can lead to a reluctance to share one's own, or a child's autism diagnosis with others. Despite research highlighting the importance of communication between teachers and parents regarding autism, there is no specific guidance given to parents on how and when to disclose an autism diagnosis to the teacher or indeed to the autistic individual themselves. Parents of autistic children frequently express concern that their child may be treated poorly or excluded if they were to disclose their child's autism diagnosis. Therefore, there are numerous autistic children in classrooms around the United Kingdom for whom their teacher is not aware of their autism.

Restricted and Repetitive Behaviours (RRB) are a visible behavioural feature of autistic children and serve as a coping strategy to help the child self-regulate. There are two types of RRB, referred to as higher order and lower order RRB. Lower order RRB often include actions such as 'hand flapping' or 'excessive' twisting of hair. Higher order behaviours often include a strong preference for routine or an intense fascination with a specific topic. Higher order RRB are considered to be more complex than lower order RRB.

Research into how teachers perceive RRB, and the factors that influence this, and the decisions made around behavioural management for RRB is sparse, but it is noted that RRB often require time-consuming management strategies and can hinder learning. An area not researched to date, however, is how autism awareness could impact on how teachers perceive and manage behaviours such as these in the classroom.

The primary aim in the study was therefore to explore the impact that autism awareness had on how teachers perceived and managed RRB.

### Method

This study used online vignettes which described classroom-based scenarios where autistic children displayed RRB. A total of 192 primary school teachers participated. Participants were randomly assigned into one of four groups which differed in terms of whether the

participants were aware of the child's autism diagnostic or not, and the type of RRB presented in the scenario.

The teachers were asked to select a strategy for managing the behaviour in the scenario and rate how effective this strategy would be. Participants also rated how they perceived the RRB in terms of how likely the behaviour was to persist over time, how much volitional control the child had over the behaviour, and whether the behaviour was driven by environmental factors, or factors specific to the child.

## Key Findings

- Teachers perceived higher order RRB as more volitional than lower order RRB.
- Being aware of the autism diagnosis led to teachers to believe that RRBs would be more consistent over time but also perceive them as amenable to effective intervention.
- Teachers aware of the child's autism diagnosis were more likely to perceive the RRB as being due to factors specific to the child, than teacher who were unaware of the child's diagnosis.
- Collaborative interventions were preferred for higher order RRB regardless of whether the teachers were aware of the autism diagnosis or not.
- For lower order RRB a collaborative intervention was more likely when teachers were aware of the autism diagnosis than when they were not.
- Teachers rated their behavioural management strategy as more effective for higher order RRB than for lower order RRB, but only when they were aware of the autism diagnosis.
- Teachers rated the effectiveness of their behavioural management strategy higher when they aware of the autism diagnosis compared to when they were not aware.
- Teacher's level of experience predicted how effective they rated their behavioural management strategy.

## Conclusions

The findings suggest that autism diagnostic disclosure shapes how teachers perceive autistic behaviours, how they intervene to manage these behaviours, and how effective they feel this intervention will be at managing these behaviours in a classroom setting.

The results suggest it could be helpful for clinicians to share with parents of autistic children and autistic charities; the positive impact diagnostic disclosure could have in facilitating collaborative engagement and effective behavioural management in the classroom.

## Limitations and Future Developments

Several limitations of the study must also be acknowledged. It could be argued that the classroom-based vignettes cannot capture the true nature of a real-life classroom. This means the results may not truly reflect how teachers would perceive and manage behaviours in a real-life situation. Future studies could explore whether the findings can be replicated with video vignettes, virtual reality (VR), or simulated classroom situations.

The study yielded an unexpected finding, that when the teachers were autistic themselves, they were more likely to choose a collaborative intervention regardless of RRB type or awareness of diagnosis. It is important to note however, that the number of autistic teachers was small. Future research with larger autistic participant samples could therefore provide important insights into the impact of teacher diagnosis on preferred intervention approaches.

## Connecting Narrative/Reflection

Prior to the Doctorate in Clinical Psychology training I completed a Neuroscience PhD. Despite relishing developing as a neuroscience researcher, I reflected that I had not worked closely enough with the patient population for which my results were most relevant. As such, I saw the Clinical Psychology Doctorate as an opportunity to carry out research rooted in neuropsychological functioning but from a more service user-centred perspective to produce clinically significant results with practical implications.

Throughout my training I have been driven me to seek out opportunities to consider adaptions in practice and communication, to suit those with a wide range of neuropsychological profiles. I therefore decided to complete research which leaned into this drive.

The theme cutting across all three projects is the recognition of invisible challenges and potential barriers to positive experience and/or engagement.

## Systematic Review of the Literature

Working in Neuropsychology services. prior to training, ignited an enthusiasm for Clinical Neuropsychology and I developed a particular interest in links between acquired brain injury and sleep disorders. I further developed this interest during my placement with the Paediatric Non-Respiratory Sleep Disorders Clinic, General Paediatrics. I had specifically requested this placement given my prior interest in this area.

I particularly enjoyed working with service users who had sleep disorders secondary to neurological conditions but felt understanding the role cognition played was missing. This led to the decision to complete a review which explored links between brain injury, sleep and cognition. I really appreciated the opportunity to devote time to developing a comprehensive understanding of this topic

## Service Improvement Project

During my placement with The Pelvic Pain service I started to see the importance of considering gaps or challenges in communication and how this can impact on clinical practice. My supervisor commented on how my creativity around communication had facilitated good engagement with service users who previously had not had good experiences.

Reflections on the importance of communication especially in formulating and treating pain naturally evolved into the Service Improvement Project.

I really valued working with the lived-experience of the service users alongside the MDT to identify a gap in the service, delve into the experience of those who really matter and make meaningful change.

## Theory Driven Project

My initial TDRP proposal was to assess the impact of attentional shifting on conditioned pain modulation. However, I had to take a break from clinical training as my partner was hospitalised with an acquired brain injury. Upon my return this TDRP was no longer a viable option as the external supervisors could no longer support access to the lab space required. That project had been quite a complex experimental study with physiological pain sensitivity assessment which I had developed during the early stages of my first placement, and which drew on my previous PhD research skills and experience. By the time I was required to develop a new project, I had moved away from wanting to conduct experimental physiological data-based research to thinking about how to capture more experiential data in clinical research.

I subsequently developed an alternative project looking at adjustment and acceptance in paediatric brain injury, which was done with collaboration with Bristol Children's Hospital with whom I have kept professional links. Despite this being a valuable and under researched area, with further exploration of practicalities, NHS recruitment was deemed too precarious. I therefore decided instead to focus on completion of a project which would have viable recruitment options, but which still afforded me the opportunity conduct meaning clinical research. Given my interest in paediatric populations, but aware of the challenges in recruitment in paediatric brain injury populations, I decided to consider populations of neurodivergent children.

I was aware that teachers are often unaware of all the pupils in their classroom who have an autism diagnosis and wondered how this affected the interplay between the child and the teacher supporting them in the classroom. I therefore decided to work with teachers and utilise online methods so that the project could be national and wide reaching. I delighted in

the wealth of responses I got from this population and the results, which generated what I feel are valuable recommendations for supporting autistic children in the classroom.

## Key Learning Points and Future Developments

I feel it is important to acknowledge that I have had a lot of setbacks, and as such have had to remain resilient. Returning to perusing a career in Clinical Neuropsychology and conducting research in related topics after having taken a break to support my partner with his neurorehabilitation and adjustment to his acquired disability, post acquired brain injury, has been and remains, hugely significant for me. It has been confronting, illuminating but hugely rewarding. Most importantly it has been affirming of my professional and personally identity which centres around valuing neuropsychological difference and clinical psychology within this context.

Managing the completing demands of the research portfolio alongside the clinical training, and subsequently alongside a full-time clinical caseload has been challenging, and has made me reflect on my own neuropsychological profile, strengths and weaknesses. I have come to consider myself as neurodiverse and have tried to be accommodating to my own difference. I have been mindful of my executive functioning challenges, which can make time-management all the more difficult, as well as my creative strengths which have provided me with adaptability and the capacity to creatively problem solve.

Conducting research as part of my doctorate has allowed me to develop my understanding and skills in planning and conducting meaningful research in a clinical setting. This has been a different but complimentary experience to PhD research experience. I have been able to develop a more comprehensive set of research skills and feel I am now a more rounded researcher.

I have also been able to incorporate learning from my research into my clinical practice, particularly in terms of working with unseen challenges, as I now work full-time in an adult neuropsychology setting working with adults who have had a stroke. Within this service I am also developing a sleep pathway.

# Appendices

## SRL Appendix A: Protocol

### Condition or Domian being studied

*Traumatic Brain Injury; Paediatric Care; Sleep disturbances; Sleep heath; Neuropsychological Testing*

### Rationale for review

Disrupted sleep health is common post traumatic brain injury (TBI) in adult and older adult populations. These sleep disturbances have also been shown to negatively impact on cognition in a range of domains. Sleep health disturbances are also reported in children post TBI, however, the links these may have with cognition are poorly characterised in comparison to their adult counterparts.

### Review Objectives

To complete a systematic review to consolidate and synthesis data on sleep health disturbance as a result of TBI and related cognitive deficits

### Background

Sleep health disturbance, in a range of forms are common post traumatic brain injury (TBI) and reportedly have a prevalence ranging from 23-84% (Albrecht & Wickwire, 2020; Ayalon, Borodkin, Dishon, Kanety, & Dagan, 2007; Barshikar & Bell, 2017; Grima, Ponsford, Rajaratnam, Mansfield, & Pase, 2016; Mathias & Alvaro, 2012; Orff, Ayalon, & Drummond, 2009; Ouellet, Savard, & Morin, 2004; Wickwire et al., 2018). Sleep health disturbances are common across TBI severity, includes even mild forms of TBI such as concussion (Mosti, Spiers, & Kloss, 2016).

Sleep is integral for cognitive processes including memory consolidation (Stickgold, 2005) emotional processing (Tempesta, Socci, De Gennaro, & Ferrara, 2018), and executive functioning (Muzur, Pace-Schott, & Hobson, 2002), and indeed sleep health disturbance post TBI has been shown to impact on cognition in adult and older adult populations (Mantua, Henry, Garskovas, & Spencer, 2017; Theadom et al., 2015; Wiseman-Hakes et al., 2013). Sleep health disturbances are also reported in children with TBI (Botchway, Godfrey, Anderson, & Catroppa, 2019; Botchway et al., 2020; Gagner, Landry-Roy, Lainé, & Beauchamp, 2015; Wilkinson et al., 2018; Williams et al., 2020), however these disturbances are considered to be poorly characterised in comparison to their adult counterparts (Luther, Poppert Cordts, & Williams, 2020).

A recent systematic review, looking at sleep health disturbances in paediatric populations, post TBI, revealed a prevalence rate of at least 20%. The paper also reported a negative correlation between sleep health disturbance and posttraumatic cognitive, behavioural, and quality of life outcomes (Luther et al., 2020). Few studies were included which assessed cognition specifically however, as this was not the primary focus of the review. The nature of cognitive deficits in the context of sleep health disturbance post TBI was therefore not reviewed.

Given that sleep is integral for brain development (Frank, 2020; Stores, 2001) and healing after injury (Siegel, 2003; Stores, 2001), children with TBI related sleep health disruption are at risk significant functional deficits neurodevelopmentally and cognitively (Tham et al., 2012). Injuries disrupting sleep during critical periods for function development therefore have a significant impact the trajectory of neurocognitive function development (Muzur et al., 2002).

Despite the clinical need for greater understanding of the interweaving impact of sleep health disruption on cognition post TBI in developing children and adolescence, sleep health disruption has not been evaluated systemically alongside cognitive deficits in paediatric and adolescent populations post TBI.

A systematic review and narrative synthesis will therefore be conducted to firstly, characterise sleep health disruption in children and adolescents post TBI and secondly, to characterise neurocognitive performance of children and adolescents post TBI. Due to the fact this review is in area which is under researched both papers looking broadly at cognition and papers investigating specific cognitive domains will be included.

Given the purpose of the review is to consolidate and synthesis data on sleep health disturbance as a result of TBI and related cognitive deficits, where there is mention of participants having a pre-morbid neurodevelopmental disorder such as autism (Ballester, Richdale, Baker, & Peiro, 2020; Carmassi et al., 2019; Cohen, Conduit, Lockley, Rajaratnam, & Cornish, 2014) or chronic health conditions such as chronic pain (Evans, Djilas, Seidman, Zeltzer, & Tsao, 2017; Long, Krishnamurthy, & Palermo, 2008) studies will be excluded from the review as these conditions are considered to cause sleep health disturbance.

## Method

### Type and method of review

Systematic review and narrative review (Popay et al., 2006).

**Libraries**

EMBASE, PsycINFO, MEDLINE and AMED (via Ovid), SCOPUS.

The search strategy has been designed to combine four groups of key terms pertaining to TBI, the child and adolescent population, sleep/fatigue issues and cognitive deficits. Appropriate truncations and possible misspellings will be included.

**Types of study to be included**

Given this area of research is in its infancy it has been decided that it would be best to include a range of designs including: single case designs, case report/series, case-control studies and longitudinal designs.

Eligibility criteria to include for each study:

1) participants who have sustained a mild to severe traumatic brain injury
2) participants aged 3-25 years of age (age ranges where cognitive domains for review are assessable)
3) where the presence of sleep health disturbances has been assessed and/or quantified (using objective and/or objective self and parent report measures as per below)
4) where there has been assessment of cognitive functioning (using standardised age appropriate neuropsychological assessments and/or self and parent reported questionnaire measures as per below)
5) Published years 2002–present
6) English language

Exclusion Criteria:

1) Participants do not have a reported pre-morbid sleep-wake disorder

2) Participants do not have a pre-morbid neurodevelopmental disorder considered to impact on sleep such as autism or a learning disability prior to TBI.
3) Participants have a premorbid chronic health condition such as chronic pain
4) Where sleep and or cognition in the context of TBI is not the primary focus

Quality of the papers were assessed using the Mixed Measures Appraisal Tool (MMAT, with 30% assessed an additional independent reviewer. This was selected due to the heterogeneity of study designs used in the studies included in this review.

**Initial scoping**

PROSEPRO has been checked to ensure this review topic is not currently being undertaken. A preliminary search and initial scoping revealed 11 studies which met the inclusion criteria, remained following the exclusion criteria and were deemed appropriate following title and abstract screening.

**Main outcome(s)**

***Sleep***

Objective: polysomnography, actigraphy and hormonal level differences

Subjective: sleep diaries and questionnaires, sleep measures either self-report or parent report including Children's Sleep Habits Questionnaire (CSHQ), Pediatric Quality of Life Inventory (PedsQoL), PedsQL Multidimensional Fatigue Scale (PedsQL MFS), Sleep Disturbances Scale for Children (SDSC), Epworth Sleepiness Scale (ESS), Child Behaviour Checklist (CBCL), Insomnia Severity Index (ISI)

***Cognition***

Objective: Wechsler Preschool & Primary Scale of Intelligence Third Edition (WPPSI III), WPPSI IV, The Wechsler Intelligence Scale for Children Fourth Edition (WISC-IV), WISC-V, Wechsler Adult Intelligence Scale Third Edition (WAIS III), WAIS IV, Delis-Kaplan Executive Function System (DKEFS), Child and Adolescent Memory Profile (ChAMP), Children's Memory Scale (CMS), The Wechsler Memory Scale – Third UK Edition (WMS–III), WMS-IV UK, Clinical Evaluation of Language Fundamentals-Fourth Edition (CELF-4), CELF 5, Continuous Performance Task (CPT), Immediate Post-Concussion Assessment and Cognitive Testing (ImPACT), Galveston Orientation and Amnesia Test (GOAT)

Subjective: self or parent reported difficulties as per consultation or on questionnaire based measure including: Adaptive Behaviour Assessment System Second (ABAS-2), ABAS-3, PedsQoL, Behavior Assessment System (BASC), BASC-2, Child Behavior Checklist (CBCL), Parent Memory Questionnaire (PMQ) Child memory Questionnaire (CMQ), Multidimensional Fatigue Scale (PedsQL MFS- Cognitive Fatigue subscale)

**Measures of effect**

Given the heterogeneous nature of designs and associated analyses to be included in the review, a variety of outcomes were extracted and synthesised.

For group comparisons, an effect will be recorded and synthesised when authors report a statistically significant difference between groups (using appropriate parametric or non-parametric test) at a threshold of $p < .05$.

For regression/correlational analyses effects will be recorded and synthesised when authors report regression coefficients at statistically significant threshold of $p < .05$ with at least a small effect size $r = .2$.

Prevalence of sleep disturbance or cognitive deficit will be reported when authors included reference to measure specific clinical threshold (i.e., *T*-score).

**Data extraction (selection and coding)**

The independent reviews will extract data based on:

- patient information (demographics such as age and clinical characteristics in terms of TBI and sleep health disturbance)
- study results (which groups were compared, time points of measurement, measures of central tendency and dispersion, effect size, significance levels)
- main objective of the study
- subjective and objective sleep and cognitive outcomes
- authors' interpretations (presented in the discussion)
- biases and limitations

Search terms:

sleep OR sleep disorder OR sleep disturb* OR insomnia OR circadian OR parasomnia OR hypersomnia OR OR sleep-wake OR fatigue AND child OR pediatric OR paediatric OR infant OR youth OR adolescent OR OR adolescence OR young adult OR teenager AND cognition OR language OR memory OR verbal memory OR consolidation OR forget* OR recall OR attention* OR emotional processing OR affect processing OR executive OR planning OR inhibition OR cognitive flexibility AND brain injur* OR head injur* OR concussion* OR traumatic brain injur* OR head trauma OR mild traumatic brain injury OR brain trauma OR traumatic head in

## SRL Appendix B: Appropriate Objective and Subjective Measures of Cognition

| | Full Title | Abbreviation | Domains Assessed | Age Range | Reference |
|---|---|---|---|---|---|
| *Objective Measures* | Clinical Evaluation of Language Fundamentals Fourth Edition/Fifth Edition | CELF 4/CELF5 | Core, receptive, expressive language, and language structure | 5-21 | (Semel et al., 2003) |
| | Conners' Continuous Performance Test 3rd Edition | CPT-3 | Attention | 8+ | (Conners, 2000) |
| | Child Memory Scale | CMS | Memory, Attention, Learning | 5-17 | (Cohen, 1997) |
| | CNS Vital Signs Neurocognitive Battery | CNSVS | Attention, EF, processing speed | 7+ | (Gualtieri & Johnson, 2006) |
| | Child and Adolescent Memory Profile | ChAMP | Immediate and delayed verbal/visual memory | 5–21 | (Sherman & Brooks, 2015) |
| | Cogstate Computerised Cognitive Test Battery | Cogstate | Processing speed, attention, learning | 6+ | (Maruff et al., 2009) |
| | Delis-Kaplan Executive Function System | DKEFS | Executive functions | 8+ | (Delis et al., 2001) |
| | Differential Ability Scales – Second Edition | DAS-II | General cognitive ability | 2;6-17;11 | (Elliott et al., 2007) |
| | Galveston Orientation and Amnesia Test | (GOAT) | Orientation, Memory | 15+ | (Levin et al., 1979) |
| | Immediate Post-Concussion Assessment and Cognitive Testing | ImPACT | Memory, processing speed, reaction time | 5+ | (Ibarra, 2011) |
| | NEPSY–Second Edition | NEPSY-II | Attention, EF, memory, language | 3-16;11 | (Kemp & Korkman, 2010) |
| | Test of Memory Malingering | TOMM | Effort/memory validity | 16+ | (Tombaugh & Tombaugh, 1996) |

| | | | | | |
|---|---|---|---|---|---|
| | Wechsler Preschool & Primary Scale of Intelligence Third Edition/Forth edition | WPPSI III/ WPPSI IVV | Verbal comprehension, visual-spatial reasoning, working memory, fluid reasoning, and processing speed | 2;6-7;7 | (Wechsler, 2002; Wechsler, 2012) |
| | Wechsler Adult Intelligence Scale – Fourth Edition | WAIS-IV | IQ, working memory, processing speed | 16+ | (Wechsler, 2008) |
| | Wechsler Intelligence Scale for Children – Fourth/Fifth Edition | WISC-IV / WISC-V | IQ, working memory, processing speed | 6-16;11 | (Wechsler, 2003, 2014) |
| | Wide Range Achievement Test – Fourth/Fifth Edition | WRAT-4 / WRAT-5 | Reading, spelling, arithmetic | 5+ | (Wilkinson & Robertson, 2017; Wilkinson & Robertson, 2006) |
| | Wechsler Memory Scale – Third UK Edition (WMS–III | WMS-IV UK | Memory, Working Memory | 16;9+ | (Wechsler, 2009) |
| | Woodcock-Johnson Tests of Cognitive Abilities – Third Edition | WJ-III | Cognitive and academic clusters | 2+ | (Woodcock et al., 2001) |
| *Subjective Measures* | Behavior Rating Inventory of Executive Function | BRIEF / BRIEF-2 / BRIEF-P | Executive functioning (parent/teacher/self-report) | 2+ | (Gioia et al., 2000) |
| | Child Memory Questionnaire | CMQ | Memory concerns (parent/self-report) | 5-12 | (Drysdale et al., 2004) |
| | Child Behavior `Checklist | CBCL | Internalizing/Externalizing Behaviors, and Attentional/Hyperactivity concerns (parent-report) | 1;5-18 | (Achenbach & Rescorla, 2001) |
| | Multidimensional Everyday Memory Ratings for Youth | MEMRY | Memory, learning, and executive function concerns (parent-report) | 5-21 | (Sherman & Brooks, 2017) |
| | PedsQL Multidimensional Fatigue Scale Cognitive Subscale | PedsQL Cognitive Fatigue | Cognitive fatigue concerns (parent-report) | 2-18 | (Varni et al., 1998, 2002) |

| | | | | | |
|---|---|---|---|---|---|
| | Parent Memory Questionnaire/Child Memory Qustionnaire (Parent/Child) | PMQ/CMQ | Memory concerns (self-report) | 5-18 | (Kadis et al., 2004) |
| *Functional Measures* | Functional Independence Measure for Children – Cognitive Scale | WeeFIM Cognitive | Functional memory, communication, problem solving concerns (parent-report) | 0;6-21 | (Msall et al., 1994) |

## SRL Appendix C: Appropriate Sleep Measures

| Full Title | Abbreviation | Domains Assessed | Age Range | Reference |
|---|---|---|---|---|
| Actigraphy (Objective Sleep Monitoring) | Actigraphy | Sleep-wake patterns (activity based) | 1+ | (Paediatrics & Health, 2009) |
| Polysomnography | - | Physiological parameters during sleep | 2+ | (Paediatrics & Health, 2009; Sen & Spruyt, 2020) |
| Child Behavior Checklist (Sleep Cluster) | CBCL | Nightmares sleep quantity, trouble sleeping, overtiredness | 4-18 | |
| Epworth Sleepiness Scale for children and adolescents | ESS-CHAD | Daytime sleepiness | 12-18 | (Janssen et al., 2017; Johns, 1991) |
| Insomnia Severity Index | ISI | Sleep onset, maintenance, dissatisfaction, disturbance severity | 5+ | (Denis et al., 2023; Morin et al., 2011) |
| Post-Concussion Symptom Scale – Sleep Items | PCSS | Difficulties falling or staying asleep, excessive somnolence and sleep quantity | 2+ | (Lovell et al., 2006; Podolak et al., 2021) |
| Sleep Disturbance Scale for Children | SDSC | Difficulties initiation/maintenance of sleep, breathing disorders, arousal, excessive somnolence | 3–18 | (Bruni et al., 1996; Romeo et al., 2013) |
| Children's Sleep Habits Questionnaire | CSHQ | Bedtime behaviour, sleep duration, night wakings, parasomnias, sleep-disordered breathing | 2-16 | (Owens et al., 2000; Sneddon et al., 2013) |
| Insomnia Severity Index | ISI | Sleep onset, maintenance, dissatisfaction, disturbance severity | 5+ | (Denis et al., 2023; Morin et al., 2011) |
| PedsQL Multidimensional Fatigue Scale | PedsQL-MFS (sleep/rest) | Restorative sleep, daytime tiredness, sleep-related fatigue | 2–18 | (Varni et al., 1998, 2002) |
| Pediatric Sleep Disturbance & Sleep-Related Impairment | PROMIS | Difficulty falling/staying asleep, excessive somnolence | 5–17 | (Forrest et al., 2018) |

| | | | | |
|---|---|---|---|---|
| Post-Concussion Symptom Inventory – Sleep Items | PCSI | Difficulty falling/staying asleep, excessive somnolence | 5–18 | (Sady et al., 2014) |

## SRL Appendix D: Search Strategy

*Ovid:*

(((brain adj5 injury) or (head adj5 injury) or concussion or tbi or mtbi) and (child or pediatric or paediatric or infant or youth or adolescent or adolescence or teenager or adolescents or children or preschooler) and (cognition or cognitive or language or memory or consolidation or forget or recall or attention or processing or affect or executive or planning or functioning) and (sleep or insomnia or circadian or parasomnia or hypersomnia or sleep-wake or fatigue)).tw,kf

*Scopus:*

TITLE-ABS( ( ("brain" W/1 "injury") OR ("head" W/1 "injury") OR concussion OR tbi OR mtbi ) AND ( child OR pediatric OR paediatric OR infant OR youth OR adolescent OR adolescence OR teenager OR adolescents OR children OR preschooler ) AND ( cognition OR cognitive OR language OR memory OR consolidation OR forget OR recall OR attention OR processing OR affect OR executive OR planning OR functioning ) AND ( sleep OR insomnia OR circadian OR parasomnia OR hypersomnia OR "sleep-wake" OR fatigue

**SRL Appendix E: Mixed Methods Appraisal Tool (MMAT), version 2018**

| Category of study designs | Methodological quality criteria | Responses | | | |
|---|---|---|---|---|---|
| | | Yes | No | Can't tell | Comments |
| Screening questions (for all types) | S1. Are there clear research questions? | | | | |
| | S2. Do the collected data allow to address the research questions? | | | | |
| | *Further appraisal may not be feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.* | | | | |
| 1. Qualitative | 1.1. Is the qualitative approach appropriate to answer the research question? | | | | |
| | 1.2. Are the qualitative data collection methods adequate to address the research question? | | | | |
| | 1.3. Are the findings adequately derived from the data? | | | | |
| | 1.4. Is the interpretation of results sufficiently substantiated by data? | | | | |
| | 1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation? | | | | |
| 2. Quantitative randomized controlled trials | 2.1. Is randomization appropriately performed? | | | | |
| | 2.2. Are the groups comparable at baseline? | | | | |
| | 2.3. Are there complete outcome data? | | | | |
| | 2.4. Are outcome assessors blinded to the intervention provided? | | | | |
| | 2.5 Did the participants adhere to the assigned intervention? | | | | |
| 3. Quantitative non-randomized | 3.1. Are the participants representative of the target population? | | | | |
| | 3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)? | | | | |
| | 3.3. Are there complete outcome data? | | | | |
| | 3.4. Are the confounders accounted for in the design and analysis? | | | | |
| | 3.5. During the study period, is the intervention administered (or exposure occurred) as intended? | | | | |

| | | | | | |
|---|---|---|---|---|---|
| 4. Quantitative descriptive | 4.1. Is the sampling strategy relevant to address the research question? | | | | |
| | 4.2. Is the sample representative of the target population? | | | | |
| | 4.3. Are the measurements appropriate? | | | | |
| | 4.4. Is the risk of nonresponse bias low? | | | | |
| | 4.5. Is the statistical analysis appropriate to answer the research question? | | | | |
| 5. Mixed methods | 5.1. Is there an adequate rationale for using a mixed methods design to address the research question? | | | | |
| | 5.2. Are the different components of the study effectively integrated to answer the research question? | | | | |
| | 5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted? | | | | |
| | 5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed? | | | | |
| | 5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved? | | | | |

**Reporting the results of the MMAT (version 2018)**

In the version 2018, we advised not to present an overall score. This decision was made from the literature that discouraged to use metrics because it is not informative. By presenting a single number, it is not possible to know what aspects of studies are problematic. We often see people presenting a global score and nothing else in the results or discussion or description of included studies. This often raises the question of why quality appraisal was performed.

This suggestion is, however, problematic for reporting the results of the MMAT. Several MMAT users have contacted us for advice to report their results. If there is a need to report an overall score, here is a suggestion based on the previous version of the MMAT: For each retained study, an overall quality score may not be informative (in comparison to a descriptive summary using MMAT criteria), but might be calculated using the MMAT. Since there are only a few criteria for each domain, the score can be presented using descriptors such as

stars (*) or %:
5***** or 100% quality criteria met
4 **** or 80% quality criteria met
3 *** or 60% quality criteria met
2 ** or 40% quality criteria met
1 * or 20% quality criteria met

For mixed methods studies, since there are 15 criteria to rate (instead of 5), the premise is that the overall quality of a combination cannot exceed the quality of its weakest component. Thus, the overall quality score is the lowest score of the study components. The score is 20% (*) when QUAL=1 or QUAN=1 or MM=1; it is 40% (**) when QUAL=2 or QUAN=2 or MM=2; it is 60% (***) when QUAL=3 or QUAN=3 or MM=3; it is 80% (****) when QUAL=4 and QUAN=4 and MM=4, and it is 100% (*****) when QUAL=5 or QUAN=5 or MM=5; (QUAL being the score of the qualitative component; QUAN the score of the quantitative component; and MM the score of the mixed methods component).
Regarding questions on cut off value, we have not studied values that could characterize low, medium or high quality studies. The categories are arbitrary, but useful for performing qualitative or quantitative sensitivity analysis. We have seen some papers with 2 categories (lower vs higher quality) or 3 categories (e.g., low, medium, and high). What is important is to clearly describe how the results of the appraisal were interpreted and used in the review (transparency).

Examples of tables presenting the results of the MMAT:

| Studies | Criteria from the Mixed Methods Appraisal Tool | | | | | | | | | | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | 1.1 | 1.2 | 1.3 | 1.4 | 1.5 | 2.1 | 2.2 | 2.3 | 2.4 | 2.5 | 3.1 | 3.2 | 3.3 | 3.4 | 3.5 | 4.1 | 4.2 | 4.3 | 4.4 | 4.5 | 5.1 | 5.2 | 5.3 | 5.4 | 5.5 |
| Author, date | 0 | 1 | 1 | 1 | 1 | | | | | | | | | | | 1 | 0 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 |
| Author, date | | | | | | | | | | | 0 | 1 | 1 | 1 | 1 | | | | | | | | | | |
| Author, date | | | | | | 1 | 1 | 1 | 0 | 1 | | | | | | | | | | | | | | | |
| ..... | | | | | | | | | | | | | | | | | | | | | | | | | |

Table of characteristics of the included studies with a column on the overall score of each study

| Studies | Country | Population | Intervention | Comparator | Outcome | .... | Quality |
|---|---|---|---|---|---|---|---|
| Author, date | | | | | | | ***** |
| Author, date | | | | | | | * |
| Author, date | | | | | | | *** |
| ... | | | | | | | |

## SRL Appendix F: Guide for Authors

### About the journal

### Aims and scope

Official Journal of the World Sleep Society and International Pediatric Sleep Association *Sleep Medicine* aims to be a journal no one involved in clinical sleep medicine can do without.

A journal primarily focussing on the human aspects of sleep, integrating the various disciplines that are involved in sleep medicine: neurology, clinical neurophysiology, internal medicine (particularly pulmonology and cardiology), psychology, psychiatry, sleep technology, pediatrics, neurosurgery, otorhinolaryngology, and dentistry.

The journal publishes the following types of articles: Reviews (also intended as a way to bridge the gap between basic sleep research and clinical relevance); Original Research Articles; Full-length articles; Brief communications; Controversies; Case reports; Letters to the Editor.

**Specific features include:**

Hot topic series: These focus series present four to six invited review articles, written by excellent experts in the field. The series address major topics of sleep medicine, e.g. sleep related breathing disturbances, insomnia, new technologies in sleep medicine etc.). Each paper focuses on most recent developments in pathophysiology, diagnostics and clinics of various facets of the general topic.

Special issues: These series welcome individual submissions of original articles around a general topic (e.g. pediatric sleep medicine in Europe). Papers can be submitted in a defined time range. Special Section Editors manage submission and review process.

**Journal announcements**
*Sleep Medicine* has an open access companion: *Sleep Medicine: X*. Both journals share the same aims and scope, editorial team, and rigorous peer review. The difference between the journals is the access model under which the journals will publish your work and the indexation status.

**Article types**
The primary emphasis of the journal will be clinical and to this end, a number of different types of articles will be published. Each type will be aimed to provide clinically important information needed to keep up to date with the practice of sleep medicine, written in a way to foster interdisciplinary understanding and make clinical information accessible to all practitioners.

*Sleep Medicine* publishes the following types of articles:

• Original Articles dealing with diagnosis, clinical features, pathophysiology, etiology, treatment (by all relevant modalities, including pharmacological, instrumental, surgical,

behavioral, nutritional), genetics, epidemiology, natural history and prognosis of human sleep disorders will be considered for publication, provided these have not been previously published except in abstract form or have not been submitted simultaneously elsewhere.

Reports may also include technical aspects of sleep medicine, which are relevant for diagnosis, pathophysiology, etiology, treatment and natural history. Basic research articles will also be published where they have a direct impact on or shed considerable light on clinical aspects of sleep. Submission of original articles based on animal or human experimental studies are encouraged, and these articles should include a comment in the abstract and discussion about the potential clinical relevance of the study.

• Review articles on all aspects of clinical sleep medicine and related basic science that contribute to understanding clinical sleep medicine will be published. Reviews will be timely, emphasize areas undergoing new development, and include both state of the art reviews and multi-author discussion of controversial areas.

• Editorials on manuscripts published elsewhere in the journal or on a timely and controversial topic will be published occasionally. Editorials may contain up to 1000 words and 20 references.

• Brief Communications are preliminary or limited results of investigations (up to 1500 words containing 20 or fewer references, one table and one figure).

• Letters to the Editor addressing articles appearing in the journal or on other current topics will be published (up to 300 words and five references).

• Historical Issues in *Sleep Medicine* submissions dealing with sleep-related historical figures, whether leaders from the past or characters from literature or mythology, will be considered for publication.

•Book Reviews are also published. Upon reception of a book from the publisher, it is sent to the book review editor.

• Images in *Sleep Medicine* submissions should derive from a specific sleep-related clinical situation. Each submission *must* consist of high-resolution images (e.g. polysomnographic tracing, actigraphic recording, neuroimaging, etc.) and should be accompanied by a very brief clinical impression, significance of the findings and figure legend. Readers will be encouraged to foster discussion of any controversial images. Submissions may contain up to 500 words and five references, and content must be organized by the following headings: 1. Introduction to the case, 2. Image analysis, 3. Discussion, and 4. References. Submissions not adhering to these guidelines may be rejected without further consideration.

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We advise you to read the Sex and Gender Equity in Research (SAGER) guidelines and the SAGER checklist (PDF) on the EASE website, which offer systematic approaches to the use of sex and gender information in study design, data analysis, outcome reporting and research interpretation.

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[2] J. van der Geer, T. Handgraaf, R.A. Lupton, 2022. The art of writing a scientific article. Heliyon. 19, e00205. https://doi.org/10.1016/j.heliyon.2022.e00205.
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[3] W. Strunk Jr., E.B. White, The Elements of Style, fourth ed., Longman, New York, 2000.
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[4] G.R. Mettam, L.B. Adams, How to prepare an electronic version of your article, in: B.S. Jones, R.Z. Smith (Eds.), Introduction to the Electronic Age, E-Publishing Inc., New York, 2020, pp. 281 - 304.
Reference to a website:
[5] Cancer Research UK, Cancer statistics reports for the UK. http://www.cancerresearchuk.org/aboutcancer/statistics/cancerstatsreport/, 2023 (accessed 13 March 2023).

Reference to a dataset:

[6] M. Oguro, S. Imahiro, S. Saito, T. Nakashizuka, Mortality data for Japanese oak wilt disease and surrounding forest compositions [dataset], Mendeley Data, v1, 2015. https://doi.org/10.1234/abc12nb39r.1.
Reference to software:
[7] E. Coon, M. Berndt, A. Jan, D. Svyatsky, A. Atchley, E. Kikinzon, D. Harp, G. Manzini, E. Shelef, K. Lipnikov, R. Garimella, C. Xu, D. Moulton, S. Karra, S. Painter, E. Jafarov, S. Molins, Advanced Terrestrial Simulator (ATS) v0.88 [software], Zenodo, March 25, 2020. https://doi.org/10.1234/zenodo.3727209.
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## SIP Appendix A: OUH Project Approval



### Clinical Improvement Module

| | |
|---|---|
| Number: | **7115** |
| Page: | **03 - Approved Local Audit** |
| Title: | **Autistic Spectrum Disorder (ASD) in the Chronic Pelvic Pain Service (CPPS): What proportion of patients accessing the service have a known or possible diagnosis of ASD and what is their experience of the service?** |
| Request Date: | **30/08/2021** |
| Target Date: | **31/03/2022** |
| Start Date: | **/ /** |
| Project Lead: | **Emma Evans** |
| Project Supervisor: | **Emma Evans** |
| Manager Feedback: | |

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**SIP Appendix B: PIS/Invite**

Oxford University Hospitals
NHS Foundation Trust

Chief Investigator: Dr Emma Evans,
Principal Clinical Psychologist
John Radcliffe Hospital Women's Centre
Emma.evans@ouh.nhs.uk

For questions or interest, please contact:
Amy Spray, Trainee Clinical Psychologist
amy.spray@ouh.nhs.uk

Dear

Thank you for taking the time to read this letter. I am writing to you as you are or have been under the care of the Pelvic Pain Service (PPS) and are invited to participate in a service improvement study for this service. You may have previously received this invitation but due to unforeseen circumstances a follow-up wasn't arranged at this time.

**Research Outline and Aims**

Part one of the research project has been to ascertain how common it is for service users at the PPS to have a diagnosis of Autism Spectrum Disorder (ASD) mentioned within our clinical note system. We will be comparing this data from the general population.

Part two will be involve inviting and working with service users at the PPS identified as having a diagnosis of ASD to explore their experience of the following aspects of the PPS : initial multi-disciplinary team (MDT) assessment, materials/methods of information communication and group intervention. Specific recommendations to improve engagement and experience within these areas of the PPS will be identified and feedback to the PPS team.

The study will be completed primarily by a trainee clinical psychologist, studying at Oxford University with experience working within the PPS. The study outcomes will also then be shared and discussed with the wider PPS team.

**Why have you been contacted?**

You have been identified as an individual with knowledge and experience of the PPS service and have a diagnosis of ASD mentioned within our clinical note system and are therefore being invited to participate in part two of the research project. The second part of the project will involve a one hour interview being carried out to gather the perspective on a range of aspects of the PPS (detailed above). I would be very grateful if you would be willing to complete this interview and offer your insight, perspective and experience of the PPS.

Both the PPS and the Oxford Clinical Doctorate program recognise the enormous value of collaborating with and hearing the perspective of people with lived experience of mental and physical health problems and are aiming to promote the inclusion of their voices in research and service development. Your involvement and participation would therefore be greatly appreciated on this research project should you be interested in getting involved!

**Do I have to take part?**

No. Participation in this study is voluntary. It is completely up to you whether or not you participate.

If you do decide to participate, please contact us; our contact details are provided at the end of this information sheet.

**What happens next?**

If you would be willing to participate or discuss this prospect further, feel free to email me at (amy.spray@ouh.nhs.uk) we could arrange a phone call, virtual meeting or meeting in person at the Women's Centre, John Radcliffe. If you later change your mind, you are free to withdraw from some or all of the study at any time without needing to give us a reason. This will have no impact on any clinical care you receive either currently or in the future. If you decide not to participate, you do not need to take further action and it will not affect the treatment you receive now or in the future. I will complete a follow-up phone call in the near future to discuss this with you.

With Kind regards

Amy Spray
Trainee Clinical Psychologist

Dr Emma Evans
Principal Clinical Psychologist

## SIP Appendix C: Interview Schedule

Introduction

*You have been invited to participate as you have been under the care of the Pelvic Pain Service (PPS) and been identified as having a diagnosis of Autism Spectrum Disorder (ASD). Thank you for agreeing to participate in this interview. We are interviewing you to better understand and learn from service users experiences of the PPS. There are no right or wrong answers to any of our questions, we are interested in your own experiences.*

*Participation in this study is voluntary and your decision to participate, or not participate, will not affect the care you currently receive from PPS. The interview should take approximately one hour depending on how much information you would like to share. With your permission, I would like to audio record the interview because I don't want to miss any of your comments. All responses will be kept confidential. This means that your de-identified interview responses will only be shared with research team members and we will ensure that any information we include in our report does not identify you as the respondent. You may decline to answer any question or stop the interview at any time and for any reason. Are there any questions about what I have just explained.*

*I would like to talk to your experience of the PPS, specifically your initial assessment appointment, the materials and communication and group-based interventions.*

Initial multi-disciplinary team (MDT) assessment

*I'd like to talk to you about your initial appointment with the PPS. Can you briefly talk me through your session, this was most likely carried out with multiple professionals present.*

Prompts:

- *Who was present for your assessment?*
- *Did you bring a family member or partner?*
- *Was the assessment completed online or in person?*
- *What can you remember about the space it was conducted in?*
- *Did you think the team listened and understood what was important to you? Can you describe an example?*
- *How did the professionals completing the assessment make you feel? Did any of them do anything you specifically liked or disliked?*
- *Is there something you wish all of them would do, or perhaps something you wished they wouldn't do?*
- *Is there anything that stands out in your memory about the session?*
- *Was a physical examination part of your assessment? If so, was there anything which was done which made this more or less comfortable for you?*
- *Was there anything you that was not covered in your assessment?*

Materials/methods of information communication

*Thinking back to how the appointment was set up, can you describe the process for booking the appointment and any contact you had with the PPS as part of this? If you received any written material prior to your appointment, can you briefly describe how you found these?*

Prompts:

- *How did you find the appointment booking processes?*
- *Were you happy with the level of information provided to you?*
- *How did you find communicating your pain to the clinicians?*
- *Were the assessment tools used (prior to and during the assessment) sensitive to your pain experience?*
- *Did the assessment tools and information materials capture the true nature of your pain experience?*
- *How flexible were the PPS in supporting you to meet your needs?*

Group intervention

*Can you briefly describe any group-based interventions you have either attended or were invited to with the PPS?*

Prompts:

- *What were the types of the groups offered and were they online or in person?*
- *If there was the option of online/in person, which would you prefer, and why?*
- *Is there anything that stands out in your memory about the groups?*
- *Did the groups seem accessible?*
- *Did you experience any barriers to you attending the groups? (If so, can you give an example?)*

*Is there anything else that you think it would be useful to share on any of these topic?*

## SIP Appendix D: Lay Summary

This study looked how common it is for Pelvic Pain Service (PPS) users to be autistic. We then invited autistic service users to share their experience of key aspects of the service. Service users reflected on things which they felt improved their engagement and experience such as communication being direct, and reflecting respect, compassion and non-judgment, and to promote service users' sense of agency and control as well as the option to use written information or diagrams. Service users also reflected on aspects which negatively impacted on their engagement and experience, such as uncertainty around what to expect from appointments, not being believed and sensory overload.

These findings led to recommendations, supported by the PPS, to develop video walk throughs of key aspects of the service, ensuring communication style is direct, and reflects respect, compassion and non-judgment, and to consider options for offering service users alternative places to wait for appointments which will reduce sensory overload.

The hopes are that these accommodations will improve accessibility and service user experience and engagement with the PPS for autistic individuals with pelvic pain.

## SIP Appendix E: Guide for Authors

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### Aims and scope

*Research in Autism (REIA)* publishes high quality empirical articles and reviews that contribute to a better understanding of Autism Spectrum Disorders (ASD) at all levels of description; genetic, neurobiological, cognitive, and behavioral. The primary focus of the journal is to bridge the gap between basic research at these levels, and the practical questions and difficulties that are faced by autistic individuals and their families, as well as carers, educators and clinicians. In addition, the journal encourages submissions on topics that remain under-researched in the field. We know shamefully little about the causes and consequences of the significant language and general intellectual impairments that are very common among the autism community. We know even less about the challenges that autistic women face and less still about the needs of autistic individuals as they grow older. Medical and psychological co-morbidities and the complications they bring with them for the diagnosis and treatment of ASD represents another area of relatively little research. At REIA we are committed to promoting high-quality and rigorous research on all of these issues, and we look forward to receiving many excellent submissions.

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- Submit this co-submission alongside your regular manuscript as a separate submission item; on the **'Attach files'** page in Editorial Manager, after which it will be automatically forwarded to the *Data in Brief* or *MethodsX* and assigned an editor.
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- Spelling and grammar checks have been carried out.
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We recommend that you visit our Journal Article Publishing Support Center if you have questions about the editorial process or require technical support for your submission. Some popular FAQs:

- How can I track the status of my submitted article?
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## TDRP Appendix A: Qualtrics Content

*BM Efficacy Item:*

1. How efficacious do you think you will be at managing the behaviour using the intervention you just selected?

The item was chosen from the Teachers Sense of Efficacy Scale based on a factor analysis which indicated this item most strongly assesses factors relating to a teachers' efficacy in classroom management (Fives & Buehl, 2009).

*Autism Training Items:*

1. Have you had any training in understanding and teaching autistic learners and adapting teaching practice? This must be a minimum of an hour and can have been held online or face to face.
2. Have you attended any additional training to understanding autism? This must be a minimum of an hour and can have been held online or face to face.

*Lower Order Vignette:*

During quiet reading time, Oli suddenly gets out of their seat, drops to their hands and knees and begins scraping their fingertips along the hardwood floor in a rapid, rhythmic pattern. Each scrape produces a squeak. Another child nearby grimaces at the squeaking sound, looks over to Oli, and shouts out for them to stop. Oli does not do so. The scraping quickens and becomes louder and other children start to complain.
Oli is a 9-year-old pupil in the new class you have just started working in. They have no intellectual disability.

*Intervention One:*

Work with Oli to identify what feels soothing about the scraping noise (e.g., is it the rhythm being made or the texture of the floor when scraping) and cocreate a "sensory menu" of quieter replacements—such as using a textured fidget strip—that can provide similar tactile

and auditory input. You also work to encourage Oli to signal when they need a sensory break, and to choose from the menu, to support self regulation and offer agency in selecting alternatives which are less disruptive to the class.

*Intervention Two:*

Create a sensory friendly space by adapting an area of the classroom for Oli, a quiet "sensory corner" with a range of accessible tactile materials. The is set up in a back corner of the classroom, away from direct foot traffic, windows, and high-volume activity areas. Floor mats or foam tiles are used to reduce echoes. Soft fabric curtains or a small bookshelf are positioned to create a sense of privacy and containment. The area includes silent fidget cubes, therapy putty, and textured silicone strips as well as sensory bins filled with beads or rice. There are also hand rollers and tactile tracing boards to support Oli's rhythmic needs without sound. This is to support Oli's need for rhythmic, tactile sensory input with safe and less disruptive alternatives.

*Higher Order Vignette:*

It is the start of the lesson at the beginning of term. The pupils enter the classroom and take a seat. There is no seating plan in place. When Sam arrives, their gaze is directed to a specific seat in the classroom, occupied by another pupil. Sam says quietly under their breathe "That's my seat." Their body tenses and clutching tightly onto their rucksack straps they freeze in the doorway. Another child behind Sam grunts and tells Sam to move out of the way. Sam does not. Sam's gaze remains fixed, and their breathing becomes heavier. The class is delayed in starting. Sam is a 9-year-old pupil in the new class you have just started working in. They have no intellectual disability.

*Intervention One:*

Support Sam to create or choose a portable seating identifier. This is a small personal item that Sam can place on any chair to make it feel like their own for that day. This becomes part of their routine when entering the classroom, just like hanging up a coat or collecting materials. Other students may also have indicators as part of a class-wide seating system, so Sam's support blends in. This approach provides Sam with a sense of control and

predictability regarding their seat, builds flexibility and reduces reliance on one fixed location. The strategy is designed to be subtle and inclusive, so Sam does not feel different from their peers.

*Intervention Two :*

You establish a consistent seating plan for the class. This is achieved with the use of name labels or stickers to make the seating arrangements clear for everyone. This ensures Sam is assigned to the same seat they initially gravitated toward to support their sense of familiarity and safety. A simple seating chart is printed on a classroom wall. You also prepare a personal copy of the seating plan which will be available for each student so that Sam's support blends in. The strategy is designed to be subtle, so Sam does not feel different from their peers.

*Attribution Items:*

Locus

Please think about the scenario you just read and the behaviour which was described and rate the extent to which you agree with the following statements by selecting the number that best represents your opinion.

This behaviour is primarily due to internal factors related to the pupil themselves.

1 – Strongly Disagree
2 – Disagree
3 – Neutral
4 – Agree
5 – Strongly Agree

Consistency

Please think about the scenario you just read and the behaviour which was described and rate the extent to which you agree with the following statements by selecting the number that best represents your opinion.

This behaviour will be consistent over time and unlikely to change.

1 – Strongly Disagree
2 – Disagree
3 – Neutral
4 – Agree

5 – Strongly Agree

Controllability

Please think about the scenario you just read and the behaviour which was described and rate the extent to which you agree with the following statements by selecting the number that best represents your opinion.

The pupil had control over the factors which led to the behaviour.

1 – Strongly Disagree
2 – Disagree
3 – Neutral
4 – Agree
5 – Strongly Agree

## TDRP Appendix B: Design of Vignettes

*Design of Vignettes*

Recent research into teachers' attributional beliefs has successfully used descriptive vignettes to elicit participant responses (Welsh et al., 2019). Quasi-experiment with descriptive vignettes was therefore chosen as a method for scenario delivery for the current study.

The vignettes and intervention examples were written in collaboration with the stakeholder group so that the content reflected their experience in the classroom to increase ecological validity.

Eight vignettes were developed in collaboration with the stakeholder group who have experience working with autistic children with RRB. The vignettes each outlined a scenario with a child exhibiting a RRB, describing either a higher order RRB behaviour or a lower order RRB. Two vignettes (one higher order RRB and one lower order RRB) were then selected from these eight vignettes based on which two vignettes were most comparable in terms of 'severity' and 'frequency' of behaviour.

In order to reduce the variability between vignettes and possible factors that could influence participant response, the children described in the vignettes are not referred to using a gendered pronoun (i.e., he or she), are described as aged 9-years-old to be inclusive of children in an age range associated with both lower and higher order RRB. The children are explicitly described as not having a learning disability, as cognitive abilities have been shown to impact attributional beliefs (Panganiban & Kasari, 2023).

The vignettes described a classroom situation where the teacher would be required to intervene (e.g. the described behaviour impacts upon another child or the teacher). This was to encourage participants to consider which form of intervention would be necessary.

The content developed with Stake Holder Group was inputted into ChatGPT to organise and produce the four vignettes and intervention choices to ensure consistency in writing style and length. Chat GPT was not used in a generative capacity.

The final two vignettes underwent validation by 10 Primary School Teachers (independent of the stakeholder group). Vignettes were rated on the degree to which they described the following key dimensions:  a behaviour which challenges, a behaviour you might expect from an autistic child, a lower order RRB, a higher order RRB, a collaborative/inclusive intervention and an environmental intervention.

Validation process indicated that all key dimensions (apart from behaviour which challenges) were rated as between 4-5. Behaviour which challenges was rated between 2-5. See Appendix A for Vignettes and Appendix C for Validation tool.

## TDRP Appendix C: Vignette Validation Tool

**Definitions:**

**Behaviour which challenges**: A behaviour of such intensity, frequency or duration that the physical safety of the person or others is likely to be placed in jeopardy, of the behaviour which is likely to seriously limit the use of or result in the person being denied access to ordinary community facilities.

**Autistic Child**: A child with persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive, see text):

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
2. Deficits in nonverbal communicative behaviours used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behaviour to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

**Lower order repetitive and restrictive behaviour**: Behaviours which are characterised by motor mannerisms (e.g., hand flapping), repetitive use of objects (e.g. excessive twisting of hair), are often sensory seeking, and have a physiological drive.

**Higher order repetitive and restrictive behaviour**: Behaviours which include rituals, strong preference for routine or an intense fascination with a specific topic.

**Collaborative/inclusive based approach to intervention**: Working together with the pupil to determine the intervention.

**Environmental based approach to intervention:** Modification of the environmental factors e.g., sensory aspects the classroom.

Please indicate the extent to which you agree or disagree with each of the following statements by selecting the number that best represents your opinion. Please use the above definitions for reference.

1 – Strongly Disagree
2 – Disagree
3 – Neutral
4 – Agree
5 – Strongly Agree

| | | | | | |
|---|---|---|---|---|---|
| 1. | Vignette 1 describes behaviour which challenges. | 1 ☐ | 2 ☐ | 3 ☐ | 4 ☐ | 5 ☐ |
| 2. | Vignette 2 describes behaviour which challenges. | 1 ☐ | 2 ☐ | 3 ☐ | 4 ☐ | 5 ☐ |
| 3. | Vignette 1 describes behaviour you might expect from an autistic child. | 1 ☐ | 2 ☐ | 3 ☐ | 4 ☐ | 5 ☐ |
| 4. | Vignette 2 describes behaviour you might expect from an autistic child. | 1 ☐ | 2 ☐ | 3 ☐ | 4 ☐ | 5 ☐ |
| 5. | Vignette 1 describes a lower order repetitive and restrictive behaviour. | 1 ☐ | 2 ☐ | 3 ☐ | 4 ☐ | 5 ☐ |

| | | | | | |
|---|---|---|---|---|---|
| 6. Vignette 2 describes a higher order repetitive and restrictive behaviour. | 1 ☐ | 2 ☐ | 3 ☐ | 4 ☐ | 5 ☐ |
| 9. Intervention 1 describes a collaborative/inclusive approach to intervention. | 1 ☐ | 2 ☐ | 3 ☐ | 4 ☐ | 5 ☐ |
| 10. Intervention 2 describes an environmental based approach to intervention. | 1 ☐ | 2 ☐ | 3 ☐ | 4 ☐ | 5 ☐ |
| 11. Intervention 4 describes a collaborative/inclusive based approach to intervention. | 1 ☐ | 2 ☐ | 3 ☐ | 4 ☐ | 5 ☐ |
| 12. Intervention 4 describes an environmental based approach to intervention. | 1 ☐ | 2 ☐ | 3 ☐ | 4 ☐ | 5 ☐ |

*Vignette 1:*

During quiet reading time, Oli suddenly gets out of their seat, drops to their hands and knees and begins scraping their fingertips along the hardwood floor in a rapid, rhythmic pattern. Each scrape produces a squeak. Another child nearby grimaces at the squeaking sound, looks over to Oli, and shouts out for them to stop. Oli does not do so. The scraping quickens and becomes louder and other children start to complain. Oli is a 9-year-old pupil in the new class you have just started working in. They have no intellectual disability.

*Intervention 1:*

Work with Oli to identify what feels soothing about the scraping noise (e.g., is it the rhythm being made or the texture of the floor when scraping) and co-create a "sensory menu" of quieter replacements—such as using a textured fidget strip—that can provide similar tactile and auditory input. You also work to encourage Oli to signal when they need a sensory break, and to choose from the menu, to support self-regulation and offer agency in selecting alternatives which are less disruptive to the class.

*Intervention 2:*

Create a sensory-friendly space by adapting an area of the classroom for Oli, a quiet "sensory corner" with a range of accessible tactile materials. The is set up in a back corner of the classroom, away from direct foot traffic, windows, and high-volume activity areas. Floor mats or foam tiles are used to reduce echoes. Soft fabric curtains or a small bookshelf are positioned to create a sense of privacy and containment. The area includes silent fidget cubes, therapy putty, and textured silicone strips as well as sensory bins filled with beads or rice. There are also hand rollers and tactile tracing boards to support Oli's rhythmic needs without sound. This is to support Oli's need for rhythmic, tactile sensory input with safe and less disruptive alternatives.

*Vignette 2:*

It is the start of the lesson at the beginning of term. The pupils enter the classroom and take a seat. There is no seating plan in place. When Sam arrives, their gaze is directed to a specific seat in the classroom, occupied by another pupil. Sam says quietly under their breathe “That’s my seat.” Their body tenses and clutching tightly onto their rucksack straps they freeze in the doorway. Another child behind Sam grunts and tells Sam to move out of the way. Sam does not. Sam’s gaze remains fixed, and their breathing becomes heavier. The class is delayed in starting. Sam is a 9-year-old pupil in the new class you have just started working in. They have no intellectual disability.

*Intervention 3:*

Support Sam to create or choose a portable seating identifier. This is a small personal item that Sam can place on any chair to make it feel like their own for that day. This becomes part of their routine when entering the classroom, just like hanging up a coat or collecting materials. Other students may also have indicators as part of a class-wide seating system, so Sam’s support blends in. This approach provides Sam with a sense of control and predictability regarding their seat, builds flexibility and reduces reliance on one fixed location. The strategy is designed to be subtle and inclusive, so Sam does feel different from their peers.

*Intervention 4:*

You establish a consistent seating plan for the class. This is achieved with the use of name labels or stickers to make the seating arrangements clear for everyone. This ensures Sam is assigned to the same seat they initially gravitated toward to support their sense of familiarity and safety. A simple seating chart is printed on a classroom wall. You also prepare a personal copy of the seating plan which will be available for each student so that Sam’s support blends in. The strategy is designed to be subtle and inclusive, so Sam does feel different from their peers.

**TDRP Appendix D: CUREC Application**

# CENTRAL UNIVERSITY RESEARCH ETHICS COMMITTEE (CUREC)

Ethics Application

Application: Impact of a Teacher Awareness of Autism Diagnosis on Attribution, Intervention Choice and Efficacy
ID: 1873581

| | |
|---|---|
| **Risk:** | Medium |
| **Submitted Date:** | 1 Jul 2025, 19:53 |
| **Applicant:** | Amy Spray |
| **Submitter:** | Amy Spray |
| **Principal Investigator:** | Dr. Louise Johns |
| **Org Unit:** | Oxford Institute of Clinical Psychology Training and Research (OxICPTR) |
| **Project Title:** | Impact of a Teacher Awareness of Autism Diagnosis on Attribution, Intervention Choice and Efficacy |
| **Project Duration:** | 3 Sep 2025 - 2 Mar 2027 |
| **Funder:** | |
| **Project Description:** | This study investigates how autism diagnostic awareness and Restrictive and Repetitive Behaviours (RRB) type influence teacher attributional beliefs and intervention choices. It also explores factors predicting efficacy in managing RRB and applies Weiner's theory of attribution to this context.<br><br>Restrictive and Repetitive Behaviours (RRB), a key diagnostic criterion for autism, pose a challenge in the classroom. RRB can impede academic and social learning (Azad & Mandell, 2016; Johnson et al., 2021) and could hinder a teacher's efforts to facilitate vital inclusive learning, and participation for autistic pupils. Despite this, research |

considering how teachers perceive RRB and what influences the behavioural management strategies employed is sparse.

Teacher attributional beliefs have been shown to directly influence willingness to modify teaching methods (Stein & Wang, 1988), influence emotional response (Bibou-Nakou et al., 2000) and are associated with wellbeing (Wang et al., 2015; Zee & Koomen, 2016). Certain factors, such training and years of experience have been found to moderate attributional beliefs in the classroom, but to date the influence autism diagnostic awareness exerts on attributional beliefs held by teachers remains unknown.

Autism, being an 'invisible' condition, means diagnostic disclosure is required for those around the individual to be aware of the diagnosis, and unfortunately fear of stigma coupled with power imbalances can result in a reluctance for diagnostic disclosure (O'Connor et al., 2020). Therefore, teachers are likely to have pupils in their classroom for whom their autism diagnosis has not been disclosed to them. A recent systematic review found that disclosing an autism diagnosis tended to induce positive affect and inclusive behaviours in peers (O'Connor et al., 2022), but this has not been investigated in the context of teachers and autistic pupils.

This study will utilise a vignette-based design to assess the impact that diagnostic awareness and RRB type have upon attribution beliefs and intervention choice in teachers. It will also explore what factors predict efficacy in the management of RRB. This study is the first of its kind to apply Weiner's theory of attribution (1985) to investigate attributions held by teacher about RRB in the context of autism diagnostic awareness.

The findings could be useful in directing training around RRB and offer insight into the impact that diagnosis disclosure might have on primary school teacher decision-making and their confidence in managing RRB in the classroom. the research will be published as part of a DClinPsy doctoral thesis.

**Student Project:** Yes - Research degree (e.g. PhD & MD)
**Supervisor:** Louise Johns
**Module Code:**

**SCOPE**

| | |
|---|---|
| Is this research: | Yes |
| Not research: | |
| Human Participant Involvement: | Yes |
| Research does not involve participants, tissue or personal data: | |
| Researcher division: | None of these |
| Taught student module: | No |
| SSH Minimal Risk: | |
| Any secondary data: | No |
| Secondary data only: | |
| Anonymised secondary Data: | |
| External ethics review required: | No |
| Identify NHS staff involvement: | No |
| Biological samples: | No |
| Biological samples yes: | |
| Drug or medicine: | No |
| Foodstuffs or supplements: | No |
| Medical device: | No |
| OxTREC Scope: | No |
| OxTREC minimal risk: | |

**RESEARCH TEAM**

| | |
|---|---|
| **Principal Investigator:** | Dr. Louise Johns |
| **PI Research Integrity Training:** | b. Research Integrity Refresher Course (Experienced researchers) |
| **1a. Research Integrity Core Course Date Completed:** | |
| **1b. Research Integrity Refresher Course Date Completed:** | |
| **1c. Other Date Completed:** | |
| **1c. Other Course Title:** | |
| **Is there a student:** | Yes |
| **Student Researchers:** | Array |
| **Researchers and Training:** | Array |
| **External collaborator:** | No |
| **External collaborator details:** | |
| **Medically qualified collaborator:** | No |
| **Medically qualified collaborator details:** | |
| **Conflict of Interest:** | No |
| **Conflict of Interest Details:** | |

**METHODOLOGY**

| | |
|---|---|
| **Short title:** | Teachers' Attribution, Intervention Choice and Efficacy in Managing Behaviour Which Challenges |
| **Research Summary:** | |

| | |
|---|---|
| **Location:** | |
| **Location Permission:** | No |
| **Location Permission Details:** | |
| **CUREC Approved Procedure(s):** | No |
| **CUREC Approved Procedure(s) yes:** | |
| **CUREC Best Practice Guidance:** | |
| **International Risky Travel?:** | No |
| **International Risky Travel Description:** | |
| **International Risky Travel Reduction:** | |
| **Hazardous Substances:** | No |
| **Hazardous Substances Description:** | |
| **Hazardous Substances Reduction:** | |
| **Researcher Distress Potential?:** | No |
| **Researcher Distress Potential Description:** | |
| **Researcher Distress Potential Reduction:** | |
| **Lone Working?:** | No |
| **Lone Working Description:** | |
| **Lone Working Reduction:** | |
| **Non-public Visit?:** | No |
| **Non-public Visit Description:** | |
| **Non-public Visit Reduction:** | |
| **Risk Reduction Training:** | |
| **GMO Involved?:** | No |

**GMO Involved? More Info:**

**Oversight:**

There will be monthly meetings with the research team (Louise Johns, Alice Farrington and Amy Spray) . This will be to discuss progress and/or issues and ensure the procedures set out in the study are being followed.
If there are any adverse events these will be reported and managed with the support Dr Louise Johns and Dr Alice Farrington.

**Research-specific ethical considerations:**

Consultation has been completed with teachers and a learning support assistant to ensure materials and any pertinent issues for ethical consideration have been considered and addressed.
The study design necessitates some participant deception as participants will not be told the aim of the study in full prior to participating. Deception has been kept as minimal as possible, with just specific reference to autism and RRB withheld from the participants initially. Prior to submitting study data participants will be provided with a full debrief statement on Qualtrics which will include a clear description of the deception and why this was necessary. Participants will also be provided with contact details for any concerns or complaints. Following presentation of the debrief statement participants will be told if they now wish to withdraw after having read this debrief statement, they can do so by closing their browser window without pressing 'submit', and their study data will not be submitted or saved.
Stakeholders feedback from teachers was that they did not think this would be significant deception.

**HUMAN PARTICIPANTS**

**Participants Description:**

180 (minimum) participants will be recruited. Participants will be randomly assigned to one of the four groups (n=45 in each group). The groups will be defined as follows: Group 1 - Aware of Autism Diagnosis & Lower Order Repetitive and Restrictive behaviour (RRB); Group 2 - Unaware of Autism Diagnosis & Lower Order RRB; Group 3 - Aware of Autism Diagnosis & Higher Order RRB; Group 4 - Unaware of Autism Diagnosis & Higher Order RRB.

Participants will not know they have been assigned to a specific group.

| | |
|---|---|
| | Each group will contain participants who will be self identified as a primary school teacher. See below for definition of this population/inclusion criteria. |
| **Sample size justification:** | N= 180 (minimum)- 224 (maximum), based on a power analysis completed using G*Power (Faul et al., 2007), for an ANCOVA utilising the medium effect size for a significant interaction between repetitive and restrictive behaviour type and diagnostic awareness on attribution ratings, this is based on previously reported medium effect size (Welsh et al., 2019) in order to achieve between .80 and .90 power. Statistical advice has been sought from the University of Oxford Research team members and have been review by DClinPsy research panel. |
| **Participant Inclusion Criteria:** | Inclusion criteria for participants who have self identified as a primary school teacher:<br>- Adult (over 18 years old)<br>-Primary School Teachers in England at any stage of training will be eligible. This will include those who have completed the teacher training within the last 12 months in England.<br>- Primary school teachers who are currently working in, or having worked in a mainstream school in England which covers the age range 5-11 years old, within the last 12 months will be eligible. It will also include teachers who have retired from working in a mainstream school (which covered the age range 5-11 years old), within the last 12 months. |
| **Participant Exclusion Criteria:** | - Primary school teachers who have trained outside of the United Kingdom.<br>-Primary school teachers who have not worked at a mainstream school working with pupils between the ages of 5-11 years old in England within the last 12 months. |
| **Participant Protected Characteristics:** | The study does not use any protected characteristics as exclusion criteria. |
| **Participant Identification:** | |
| **Vulnerable Participants:** | No |
| **Vulnerable Participants Description:** | |
| **Vulnerable Participants More Information:** | |
| **Participant Approach:** | |
| **Investigator Influence or Authority:** | No |

| | |
|---|---|
| **Investigator Influence or Authority detail:** | |
| **Participant Investigator Relationship:** | There are no existing relationships between the investigators and participants. |
| **Participant Recruit Information:** | Recruitment of teachers will be facilitated through public sector contacts from council and government websites e.g., publicly available SENDco contacts, through child and young person charities and through research team contacts and convenience sampling and snowball sampling methods such as University of Oxford course staff emails and contacts. The study advert and study link will be sent through the above mention means. The advert states that volunteers are needed for an online study and includes the title of the study, the aims of the research, the inclusion criteria, a summary of the what the study will entail and contact details for the PI. The study link provided alongside the advert includes the PIS, integrated means of providing consent and the content to participate in the study. The study advert and study link will be sent to above mentioned contacts when a favourable opinion from the REC has been received. |
| **Participant Decision Duration:** | There will be no time limit on consideration to participate. The research team will not be made aware of potential participants until they have decided to participate and followed the study Qualtrics link. |
| **Participants Informed Consent:** | Yes |
| **Participants Informed Consent More Info:** | Participants will access the participant information sheet and integrated consent statements via the study link on Qualtrics. No minors will be recruited.<br>Following reading through the PIS which including the following sections: -General Information -How will my data be used? -Who will have access to my data? -Who has reviewed this research? -Who do I contact if I have a concern or I wish to complain? -Do I have to take part? Participants will be asked the following statement:<br>"If you have read the information above and agree to participate with the understanding that the data you submit will be processed accordingly, please tick the box below to start." Participants will then be required to select/tick a box which states "Yes, I agree to take part. " and then click "Submit" on the online questionnaire. |
| **Participants No consent:** | |
| **Any feedback:** | No |
| **Participant Feedback:** | Following study completion (e.g. once ratings and answers to questions have been entered or if they choose to withdraw early, e.g. by closing the browser window) study participants will be provided with a debrief page which will include a clear description of the deception and why this was necessary. |

| | |
|---|---|
| | Participants will also have been provided with contact details for the PI for any concerns or complaints they may have. They will be informed that the PI will acknowledge their concern within 10 working days and give them an indication of how it will be dealt with. Participants will also be reminded that if they remain unhappy or wish to make a formal complaint they are able to contact the University of Oxford Research Governance, Ethics & Assurance (RGEA) team and given their contact details. |
| **Withdrawal Arrangements:** | The data will be collected anonymously and therefore there will not be the option to withdraw data once it has been submitted. Participants will be made aware of this. Should participants choose to withdraw either during the study or after reading the debrief they will be able to do so by closing the browser window displaying their Qualtrics submission. |
| **Withdrawal More Information:** | There are no consequences for the participants withdrawing. Participants will be assured in the PIS that there is no consequence to withdrawal from the study. If participants withdraw during completion of the study or after reading the debrief page (and indicate so by closing their browser window) their data will not be submitted. |
| **Participant Deception:** | Yes |
| **CUREC Approved Procedure 07:** | No |
| **Participant Deception More Info:** | The study design necessitates some participant deception as participants will not be told the aim of the study in full prior to participating. Deception has been kept as minimal as possible, with just specific reference to autism and RRB withheld from the participants. Following completion of the study survey questions participants will be provided with a full debrief document which will include a clear description of the deception and why this was necessary with option to exit and not submit results at that stage. Stakeholder feedback from teachers was that they did not think it was significant deception. Participants will also be provided with contact details for any concerns or complaints. |
| **Social Media:** | No |
| **Social Media More Info:** | |
| **Sensitive Topics:** | No |
| **Sensitive Topics More Info:** | |

**Illegal Behaviour:** No

**Illegal Behaviour More Info:**

**Awareness Disclosure Harm:** No

**Awareness Disclosure Harm More Info:**

**Risk of Injury:** No

**Risk of Injury More Information:**

**Risk of Injury Mitigation:**

**Invasive Procedures:** No

**Invasive Procedures More Information:**

**DBS Check:** No

**Participant Compensation:** No

**Compensation Details:**

**Undue Incentives:**

**Undue Incentives More Info:**

**Compensation After Withdrawal:**

## SECURITY

**Security More Information:**

**Security Risk Mitigation:**

**Prevent duty:** No

**Prevent duty Mitigation:**

**ENVIRONMENTAL IMPACT**

| | |
|---|---|
| **Environmental Impact:** | The research does not pose any environmental impact. |
| **Environmental Impact Monitored:** | There will not be any adverse environmental impact. |

**DATA MANAGEMENT**

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|---|---|
| **Data Type:** | -Consent statements<br>-Whether participants self-identify as autistic<br>-Teaching demographics (level of education, years teaching experience and whether they have partaken in autism specific training)<br>-Task results (Attributional ratings, Intervention Choice and Efficacy rating)<br>-Demographics including age in years, gender identity, and ethnicity |
| **Data Access Control?:** | No |
| **Data Access Control? More Info:** | |
| **Data Storage Location:** | Questionnaire data will be collected using Qualtrics. Anonymised data will be downloaded from Qualtrics to Nexus OneDrive for Business for analysis. |
| **Data Storage Period:** | The anonymised data will be stored for 3 years following project completion to allow for any amendments requested as part of DClinPsy VIVA process, and in line with the University requirements. |
| **Data Retention Reuse:** | The data will not be used in future research or made available to other research projects. |
| **Data Destruction:** | The anonymised data will be moved from Nexus OneDrive for Business to Sharepoint once the student completes the doctorate, with a date for deletion. The supervisor will delete the data at that point. |
| **Data Access:** | Anonymised data will be downloaded from Qualtrics to Nexus OneDrive for Business for analysis.<br>All analysis will be completed using SPSS. |
| **Organisation Data:** | No |

| | |
|---|---|
| **Organisation Data More Info:** | |
| **Recording:** | No |
| **Recording More Info:** | |
| **Participant Data Confidentiality:** | No identifying information will be collected during the conduct of the research or in the release of findings. |
| **Participant Data Anonymity:** | Yes |
| **Participant Data Anonymity More Info:** | No identifying information will be collected on Qualtrics during the conduct of the research or in the release of findings. |
| **Participant Data Pseudoanon:** | No |
| **Participant Data Pseudoanon More Info:** | |
| **Publication:** | |

# TDRP Appendix E: MSIDREC Approval Letter

**Medical Sciences Interdivisional Research Ethics Committee (MS IDREC)**
*Research Governance, Ethics & Assurance, Research Services, University of Oxford, Boundary Brook House, Churchill Drive, Headington, Oxford, OX3 7GB*

**Applicant**: Amy Spray
**Principal Investigator**: Dr. Louise Johns
**Department**: Oxford Institute of Clinical Psychology Training and Research (OxICPTR)

**Study title: Impact of a Teacher Awareness of Autism Diagnosis on Attribution, Intervention Choice and Efficacy**
(Version: 1.0)

**Ethics reference:** Medical Sciences Interdivisional Research Ethics Committee (MS IDREC) - 1873581

Dear Dr. Louise Johns,

On behalf of the Committee, I confirm that the above research study described in the application and other supporting documentation submitted to the committee has been carefully considered on behalf of the Medical Sciences Interdivisional Research Ethics Committee (MS IDREC) in accordance with the University's regulations and policy for ethics approval of research involving human participants, human tissue and/or personal data. The opinion is as follows:

**Opinion of Research Ethics Committee: Favourable Opinion**
**Subject to the following conditions:**
**Decision Date**: 3 Sep 2025, 14:24
**Opinion End Date**: 2 Mar 2027

If favourable, insurance-provided indemnity arrangements will be in place between the decision date and opinion end date and you may now commence your study activities. Should you plan to continue the research beyond the end date above, it is your responsibility to ensure that you request, and receive, an extension (via amendment) from the committee for indemnity to remain in place. You may be required to provide a justification.

Please note the following:

**Amendments**: Should there be any subsequent changes to the reviewed study, applications for amendments can be made via the Oxford Ethics Application System (Worktribe Ethics).

**Reports:** Studies considered by OxTREC are expected to submit an *annual progress report* on each anniversary of study approval, until the study is completed. An end of study report is also required.

**Audit**: This study may be selected for audit at the discretion of the Research Governance, Ethics and Assurance Team.

**Data safety:** It is the responsibility of the PI to ensure that all data collected during the course of the study is stored and transferred safely and securely in accordance with University requirements. Further guidance and advice are available from the Research Data Team. Additional information is available at https://researchsupport.web.ox.ac.uk/governance/ethics

Yours Sincerely

MS IDREC Ethics Officer

# TDRP Appendix F : Participation. Information Sheet and Consent

The Oxford Institute of Clinical Psychology Training and Research
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**Teachers' Attribution, Intervention Choice and Efficacy in Management of Behaviour which Challenges**

**CUREC Reference:** MS IDREC 1873581

***General Information***

The aim of this online research study is to better understand the factors that guide primary school teacher decision-making and sense of efficacy when supporting pupils who display behaviour which challenges.

We appreciate your interest in participating in this online study. You have been invited to participate as one of the following statements applies to you:

- You are a primary teacher who is currently working in a mainstream school in England with pupils aged 5-11 years of age.
- You have completed your teacher training in the UK within the last 12 months, and as part of that training have worked in a mainstream school in England with pupils aged between 5-11 years.
- You have worked as a primary school teacher in a mainstream primary school in England with pupils aged between 5-11 years, within the last 12 months.

Please read through this information before agreeing to participate (if you wish to) by ticking the 'yes' box below.

The Student Researcher is Dr Amy Spray who is attached to the Oxford Institute of Clinical Psychology Training and Research at the University of Oxford. This research is being completed under the supervision of Dr Alice Farrington and Dr Louise Johns, Oxford Institute of Clinical Psychology Training and Research at the University of Oxford.

You will be asked to read through a short vignette which describes a classroom-based scenario where a child is displaying a behaviour which challenges. You will then be asked to give an attribution rating of the behaviour (i.e., a judgement about the nature of a pupil's behaviour), select an intervention strategy, and rate your self-efficacy in managing the scenario. You will also be asked to complete a brief professional demographics and teaching experience questionnaire. The study should take no more than 15 minutes to complete. No background knowledge is required.

The data will be collected using Qualtrics and will be written up as part of the Oxford Institute of Clinical Psychology Training Doctorate thesis. There will be no third-party access to the data.

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

No. Please note that participation is voluntary. If you do decide to take part, you may withdraw at any point for any reason before submitting your answers by pressing the 'Exit' button or closing the browser. Once you have submitted your answers, it will not be possible to withdraw as responses are anonymised.

We have included a 'Prefer not to say' option for each set of questions should you prefer not to answer a specific question.

***How will my data be used?***

We will not collect any data that could directly identify you. Your IP address will not be stored. We will take all reasonable measures to ensure that data remain confidential.

The responses you provide will be stored in a password-protected electronic file on University of Oxford secure servers and may be used in academic publications and conference presentations.

Research data will be stored for 3 years after publication or public release of the work of the research, as required by the University.

***Who will have access to my data?***

The data you provide may be accessed by Dr Louise Johns, Dr Alice Farrington and Dr Amy Spray, affiliated with Oxford Institute of Clinical Psychology Training and Research at the University of Oxford.

The results will be written up for an Oxford Institute of Clinical Psychology Training doctoral thesis.

***Who has reviewed this research?***

This research has been reviewed by and received favourable opinion from a subcommittee of the University of Oxford Central University Research Ethics Committee (MS IDREC 1873581).

01865 226375, email: Louise.Johns@psy.ox.ac.uk and we will do our best to answer your query. We will acknowledge your concern within 10 working days and give you an indication of how it will be dealt with. If you remain unhappy or wish to make a formal complaint, please contact the University of Oxford Research Governance, Ethics & Assurance (RGEA) team at rgea.complaints@admin.ox.ac.uk or on 01865 616480.

**Please note that you may only participate in this survey if you are 18 years of age or over.**

☐ I certify that I am 18 years of age or over

**If you have read the information above and agree to participate with the understanding that the data you submit will be processed accordingly, please tick the box below to start.**

☐ Yes, I agree to take part

## TDRP Appendix G: Data Management

### Data management plan

Questionnaire data was collected anonymously using Qualtrics. Data was downloaded from Qualtrics to Nexus OneDrive for Business for analysis.

SPSS Version 30.00 was used to carry out all statistical analysis.

### Assumption Testing

Preliminary assumption testing was conducted to assess for normality, linearity, multicollinearity, multivariate outliers, and equality of covariance matrices. No serious violations were detected in linearity, multicollinearity, or homogeneity of covariance matrices.

Residuals were examined and found to violate the assumption of multivariate normality. However, given the large sample size (N = 192), the MANCOVA was conducted using Pillai's Trace, which is robust to such violations.

Multivariate outliers were assessed using Mahalanobis distance, with a critical value of 20.52 ($df = 5$, $p < .001$). Six cases exceeded this threshold, suggesting that their combined scores on the dependent variables were statistically atypical compared to the rest of the sample. All of these cases were participants who had identified themselves as autistic and were therefore not considered as outliers and were retained for analysis in accordance with best-practice guidelines (Tabachnick & Fidell, 2019).

## TDRP Appendix H: Instructions for Authors

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2. Check your research funder's requirements. Some research funders have rules about the type of journal you should publish in.

3. Submit your manuscript. The corresponding author must be a member of University of Oxford.

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The information below details the section headings that you should include in your manuscript and what information should be within each section.

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The title page should:

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    - "A versus B in the treatment of C: a randomized controlled trial", "X is a risk factor for Y: a case control study", "What is the impact of factor X on subject Y: A systematic review"
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- list the full names and institutional addresses for all authors
    - if a collaboration group should be listed as an author, please list the Group name as an author. If you would like the names of the individual members of the Group to be searchable through their individual PubMed records, please include this information in the “Acknowledgements” section in accordance with the instructions below
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Abstract

The Abstract should not exceed 350 words. Please minimize the use of abbreviations and do not cite references in the abstract. Reports of randomized controlled trials should follow the CONSORT extension for abstracts. The abstract must include the following separate sections:

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Keywords
Three to ten keywords representing the main content of the article.

Background

The Background section should explain the background to the study, its aims, a summary of the existing literature and why this study was necessary or its contribution to the field.

Methods

The methods section should include:

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This should include the findings of the study including, if appropriate, results of statistical analysis which must be included either in the text or as tables and figures.

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This section should discuss the implications of the findings in context of existing research and highlight limitations of the study.

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This should state clearly the main conclusions and provide an explanation of the importance and relevance of the study reported.

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Slifka MK, Whitton JL. Clinical implications of dysregulated cytokine production. Dig J Mol Med. 2000; doi:10.1007/s801090000086.

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Wyllie AH, Kerr JFR, Currie AR. Cell death: the significance of apoptosis. In: Bourne GH, Danielli JF, Jeon KW, editors. International review of cytology. London: Academic; 1980. p. 251-306.

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Blenkinsopp A, Paxton P. Symptoms in the pharmacy: a guide to the management of common illness. 3rd ed. Oxford: Blackwell Science; 1998.

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Doe J. Title of subordinate document. In: The dictionary of substances and their effects. Royal Society of Chemistry. 1999. http://www.rsc.org/dose/title of subordinate document. Accessed 15 Jan 1999.

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Healthwise Knowledgebase. US Pharmacopeia, Rockville. 1998. http://www.healthwise.org. Accessed 21 Sept 1998.

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Doe, J: Title of preprint. http://www.uni-heidelberg.de/mydata.html (1999). Accessed 25 Dec 1999.

*FTP site*
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