‘It’s designed for someone who is not me’: Reflexive thematic analysis of the healthcare experiences of autistic older adults living in the UK

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Thesis declaration form

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

Signature: 

Name: Hassan Mansour

Date: 17th November 2023

Overview

The main aim of this thesis was to explore the health challenges faced by autistic individuals across their lifespan:

In the first part, a meta-analysis examined post-traumatic stress disorder (PTSD) prevalence rates in diagnosed autistic populations, including 14 child-adolescent and 10 adult studies. Findings suggest a current prevalence of 1.25% (95%CI = 0.47; 3.24) among autistic children and adolescents, with a lifetime prevalence of 4.01% (95%CI = 3.52; 4.56). For autistic adults, the current prevalence was 1.25% (95%CI = 0.22; 6.77), with a lifetime prevalence of 1.54% (95%CI = 0.78; 3.02). Exploratory subgroup analysis suggests that assessment type, sampling source, ethnicity, gender, and intellectual disability influence prevalence rates.

The second part of the thesis included semi-structured interviews with 19 autistic adults aged 65 or older and one carer for a 68-year-old autistic adult with a co-occurring intellectual disability. Reflexive thematic analysis was used to co-construct four themes around healthcare experiences, outlining the impact of lived experiences on healthcare challenges, the influence of system and service-level changes, the intersectionality of ageing and autism, and critical policy and practice recommendations. Please note that whilst the second part was a joint project with another trainee (AG), we completed separate interviews and had different research topics (See Appendix 1).

Finally, the third part presented a critical appraisal of the entire research process, addressing conceptual and methodological challenges in the systematic review, emphasising the importance of reflexivity in the qualitative project, and reflecting on the impact of both studies on the literature and clinical practice.

Impact Statement

The meta-analysis which examined the recorded prevalence rates of post-traumatic stress disorder (PTSD) within diagnosed autistic populations, has significant clinical, research, and societal implications:

- For clinical practice, the findings highlight the importance of a nuanced and personalised approach to assessing PTSD within autistic populations. Beyond more tailored individual assessments, clinicians are urged to involve close family members or friends with the consent of the autistic individual, especially when gathering information about past traumatic experiences or current presenting difficulties.
- In the context of research, more needs to be done to investigate how assessment methods might influence current PTSD prevalence rates, especially in child-adolescent populations. The lower recorded lifetime PTSD prevalence rates in autistic adults, despite a higher likelihood of experiencing trauma, suggest the need for further research, including the exploration of subgroup differences such as sampling source, ethnicity, gender differences, and the presence of intellectual disability.
- On a broader societal level, the meta-analysis findings highlight the need to reconsider current PTSD diagnostic criteria so that they encompass a more comprehensive representation of trauma experiences faced by autistic individuals. This shift could lead to improved understanding, reduced stigma, and the development of better support systems for autistic individuals dealing with trauma.

Moving on to the qualitative study that explored the healthcare experiences of autistic older adults aged 65 years or over. It also has significant clinical, research, and societal implications:

- In terms of clinical practice, themes highlight the crucial need for healthcare services to adapt and support the unique challenges faced by autistic older adults. Therefore, it is essential for services to recognise the impact of lifelong experiences on their mental health and the anxiety they experience when accessing services. Staff must also be trained and supported to implement a more flexible and empathetic approach considering the

intersectionality between ageing and autism. Key clinical recommendations include prioritising continuity of care, implementing sensory-sensitive approaches and ensuring clear communication to reduce anxiety and improve understanding.

- From a research perspective, findings reveal significant gaps in the literature. Future lived experience research must produce specific guidelines for services and staff working with autistic adults more significantly impacted by age-related decline. Quantitative studies must also investigate the impact of system and service level changes on healthcare access rates, symptom severity, and mortality risk. There is also a need for the development of evidence-based interventions, recommendations, and policies which can improve the healthcare experiences of autistic older adults.
- Findings also highlight the need for societal awareness and inclusivity, emphasising policy changes to improve healthcare services and support structures. Active involvement of autistic individuals and their caregivers in service and policy design is crucial. Services should work towards reducing stigma, fostering understanding, and embracing a more empathetic and accommodating attitude towards autism and ageing.

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Part 1: Literature Review

Abbreviations

JS Dr Joshua Stott (Professor and Supervisor)

LO Dr Elizabeth O'Nions (Research Fellow and Supervisor)

AG Dr Amy Gillions (Previous DClinPsy Trainee)

IA Isabelle Arnold (CBT Therapist)

SK Suman Kurana (Research Assistant)

RD Dr Roopal Desai (Clinical Fellow)

AJ Dr Amber John (Research Fellow)

CEB Celine El Baou (PhD Student)

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ما فاتَكَ لم يُخلق لكَ وما خُلِقَ لكَ لن يفوتكَ

Part 1: Literature Review

Recorded prevalence rates of post-traumatic stress disorder (PTSD) among diagnosed autistic populations: a meta-analysis review

Abstract

Objective: Autistic populations are more likely to experience traumatic life events and increased mental health difficulties (Mehtar & Mukaddes, 2011; Lai et al., 2019; Turndel et al., 2022). However, there have been no meta-analyses to investigate the prevalence rates of post-traumatic stress disorder (PTSD) among diagnosed autistic populations.

Methods: A systematic literature search was conducted to identify relevant studies reporting current and lifetime PTSD prevalence rates in diagnosed autistic populations. After screening, 14 child-adolescent studies with 6,044 autistic participants and 10 adult studies with 5,140 autistic participants were included in the meta-analysis. Subgroup analyses were performed to explore the influence of factors which have been found to influence PTSD prevalence rates in neurotypical populations.

Results: After removing outliers, findings suggest the current prevalence of PTSD among diagnosed autistic children and adolescents was 1.25% (95%CI = 0.47; 3.24), with a lifetime prevalence of 4.01% (95%CI = 3.52; 4.56). For autistic adults, the current prevalence was 1.25% (95%CI = 0.22; 6.77), with a lifetime prevalence of 1.54% (95%CI = 0.78; 3.02). Whilst the child-adolescent rates are similar to those observed in the general population, the lifetime adult prevalence rates were lower than expected. Subgroup analysis suggests that gender, ethnicity, and the presence of intellectual disability impact adult lifetime prevalence rates.

Conclusion: This meta-analysis provides valuable insights into the recorded prevalence of PTSD among diagnosed autistic individuals. It underscores the complex relationship between autism and PTSD, highlighting the need to reconsider diagnostic criteria so that they more accurately identify and address trauma in autistic populations.

1. Introduction

Autism is a neurodevelopmental condition characterised by social communication and social interaction differences coupled with restricted, repetitive, or stereotypical behaviour patterns that impact overall functioning (American Psychological Association, 2022a). These characteristics should be evident during the developmental stage, typically in early childhood (WHO, 2022). However, they may also become more apparent later when social demands exceed the capacity to conceal difficulties (Happé & Frith, 2020; Guerts et al., 2021). In line with lived experience research, this review will use identity-first language because this was the preferred terminology identified by autistic individuals (Robison, 2019; Kenny et al., 2016). As such, terms such as autism and autistic individuals will be used synonymously.

1.1 Co-occurring conditions associated with autism

The global prevalence of autism spectrum condition (ASC) is estimated at 1-2%, with approximately 78 million people diagnosed worldwide (Zeidan et al., 2022; Baxter et al., 2015; Maenner et al., 2020). Autistic populations are more likely to experience physical, neurodevelopmental, and mental health difficulties (Lai et al., 2019; Muskens et al., 2017). Studies suggest that up to 70% of autistic individuals meet diagnostic criteria for one mental health difficulty, with nearly 50% having multiple co-occurring mental health difficulties (Lugnegård et al., 2011). These difficulties are observed across the lifespan, from early childhood to adulthood, and can have long-term adverse outcomes, including reduced quality of life and increased mortality if left without support (Salazar et al., 2015; Lecavalier, 2006; Simonoff et al., 2012; Hofvander et al., 2009; Schendel et al., 2016).

1.2 Traumatic life events and autism

One explanation for increased mental health difficulties among autistic populations could be due to an increased risk of experiencing adverse life events (Trundle et al., 2022). Autistic individuals often face teasing, bullying, and ostracism, which may be due to social interaction differences, making them more susceptible to victimisation (Kerns et al., 2015). Various

traumas, including experiencing physical or sexual abuse, accidents, disasters, violence, and witnessing these events occurring to others, have been reported by 26.1% of youth attending an outpatient autism clinic (Mehtar & Mukaddes, 2011). Similarly, Mandell et al. (2005) found that 30.7% of children with high-functioning autism or Asperger's syndrome in a community mental health service had experienced trauma. Moreover, parent and child survey data suggest that autistic children exhibit stronger emotional responses to traumatic events because of several vulnerability factors (Storch et al., 2013; Dell'Osso et al., 2015; Hoover, 2015). First, they may lack social support networks to aid them in the aftermath of a traumatic event. Second, language development differences might lead to difficulties in reporting abuse or distress, which may delay treatment (Cook et al., 1993).

1.3 Post-traumatic stress disorder

Post-traumatic stress disorder (PTSD) is a chronic stress condition characterised by hyperarousal or avoidance of trauma-related stimuli, re-experiencing traumatic events through intrusive symptoms, and negative alterations in cognition or mood (APA, 2022b). It is estimated that more than 70% of neurotypical individuals will experience at least one traumatic event in their lifetime, with 10% of those going on to develop PTSD (Benjet et al., 2016; de Vries & Olff, 2009). Composite international diagnostic interview methods suggest that the lifetime prevalence of PTSD within the general population ranges from 0.3 to 9.2%, with a mean of 3.2% (Dückers et al., 2016).

Similarly, data from the World Health Organisation World Mental Health Surveys administered to 26 countries between 2001 and 2012 found a lifetime PTSD prevalence of 3.9% and a 12-month current prevalence of 2.8% for neurotypical adults. However, these figures vary considerably according to country, with higher-income countries having higher PTSD prevalence rates (Koenen et al., 2017). Generally speaking, these figures are comparable to child-adolescent populations, with studies suggesting that the lifetime prevalence of PTSD varies between 1.3 to 8.1% and the current 12-month prevalence of

PTSD varies between 0.6 to 3.9% (Breslau et al., 2006; McLaughlin et al., 2013; Perkonigg et al., 2000).

1.4 Links between autism and PTSD

Although research is still in its infancy, there are theories to suggest that detail-focused orientation, executive functioning, and memory processing differences associated with autism might influence the development and maintenance of PTSD (Rumball et al., 2021; Haruvi-Lamdan et al., 2018; Hoover, 2015; Kerns et al., 2015). However, the strength and direction of this relationship remain unclear. For example, some researchers suggest that core features associated with autism could heighten fear or threat-related responses triggered by sensitivity to sensory stimuli and changes to routine or social situations (Brewin et al., 2019; Wood & Gadow, 2010). This might lead to reduced communication, fewer social interactions, and decreased coping mechanisms for processing traumatic memories (Howlin & Clements, 1995; Valenti et al., 2011).

However, others suggest that core features associated with autism may dampen fear or threat-related responses, resulting in a less distressing interpretation of the traumatic event. This might be because differences in social awareness, perception or emotion processing differences contribute to an alternative less threatening interpretation of the traumatic event (Kerns et al., 2015; Mansell et al., 1998). Finally, it is also possible that core features associated with autism have no direct impact on trauma processing, making autistic individuals equally susceptible to developing PTSD compared to neurotypical populations but also more likely to experience traumatic events throughout their lives (Cook et al., 1993; King & Desaulnier, 2011; Mansell et al., 1998).

A UK-based epidemiological study explored the impact of traumatic life events and post-traumatic symptoms in middle-aged and older adults with autistic traits (Stewart et al., 2022). Results showed that almost 30% of individuals in the high autism trait group experienced severe emotional, physical, or sexual abuse across their lifespan. This is

compared with less than 8% in the neurotypical comparison older adult group. Furthermore, the high autism trait group reported higher rates of current post-traumatic symptoms than the comparison group, with more severe symptoms observed in the high autism trait group. The study also found a significant correlation between autistic traits and trauma severity, with the effect of trauma on post-traumatic symptoms being more pronounced in individuals with high autistic traits. This correlation remained significant even after controlling for current depression and anxiety symptoms. However, they did not investigate whether these findings were replicated in diagnosed autistic populations or whether increased post-traumatic symptoms led to an official PTSD diagnosis.

1.5 Concerns related to PTSD diagnosis and autism

This lack of clarity regarding PTSD diagnosis in autistic populations is especially significant when considering the strict diagnostic criteria, particularly concerning what is regarded as a traumatic event (Weathers & Keane, 2007). Currently, a PTSD diagnosis can only be made if someone experiences extremely threatening or horrific events according to the International Classification of Diseases (ICD-11) or if they are exposed to criterion A traumas (actual or threatened death/injury to self or others) according to the Diagnostic and Statistical Manual for Mental Disorders (DSM-5; WHO, 2022; APA, 2022b). However, several studies suggest that PTSD can develop in autistic populations following non-criterion A traumas (Brewin et al., 2009; Brewin et al., 2019).

Haruvi-Lamdan et al. (2020) observed that the accumulation of adverse social events, rather than criterion A traumas, is associated with increased PTSD symptoms in autistic populations. This issue is further complicated because many autism characteristics can overlap with symptoms associated with PTSD, such as sleep difficulties, hyperarousal, and social withdrawal (Haruvi-Lamdan et al., 2018). Additionally, autistic individuals may struggle to self-report their difficulties, particularly for emotional or traumatic events (Mazefsky et al., 2011; Ben Shalom et al., 2006). This could increase the probability of diagnostic

overshadowing, where healthcare professionals misattribute PTSD symptoms to autism (Reiss et al., 1982).

1.6 Gaps within the literature

In the current literature, the prevalence rates of PTSD within autism vary significantly from 0 to 17% (Peterson et al., 2019). This variability may be due to differences in diagnostic criteria, assessment methods, sampling sources, country of origin, or study settings, among other factors (Hossain et al., 2020; Lai et al., 2019). To our knowledge, only one review has investigated the assessment and treatment of PTSD in autism (Rumball, 2019). The author concluded that assessing and treating PTSD within autistic populations is possible. That review found a mean current PTSD rate of 2.85% among eight child-adolescent studies and a mean lifetime PTSD rate of 0.8% across two adult studies.

However, the results of that review were not quantitatively synthesised in a meta-analysis, and the search was conducted more than five years ago in 2016 (Rumball, 2019). The search also included some studies that selectively recruited autistic individuals with co-occurring anxiety disorders, which may overestimate the prevalence of PTSD (Brady et al., 2000). Finally, the review did not examine the influence of sample sociodemographic characteristics. This is important because factors such as gender, ethnicity, and intellectual disability have all been found to influence PTSD diagnostic rates within neurotypical populations (Shalev et al., 2019; Alegría et al., 2013; Daveney et al., 2019).

1.7 Aims of the current review

The purpose of the current review was to gain a better understanding of the recorded prevalence rates of PTSD among diagnosed autistic individuals. To achieve this, a meta-analysis was conducted to provide the best estimates for recorded current and lifetime PTSD diagnoses in both autistic child-adolescent and adult populations. The review also aimed to identify factors such as sampling source, gender, ethnicity, presence of intellectual disability, and PTSD assessment methods that may affect overall recorded prevalence rates through

subgroup analyses. Although these subgroup analyses were exploratory, they offer insights into areas that need further investigation. Findings will also help determine whether the recorded prevalence rates of PTSD in diagnosed autistic individuals align with those observed in the general population and whether they reflect heightened post-traumatic symptoms observed in recent studies involving people with high autism traits (Haruvi-Lamdan et al., 2020; Stewart et al., 2022; Rumball et al., 2021). This can, in turn, help policymakers, services, and clinicians improve healthcare provisions for autistic individuals with PTSD.

2. Methods

This systematic review adhered to the preferred reporting items for systematic reviews and meta-analyses (PRISMA) guidelines as outlined by Moher et al. (2015). Before data extraction, the protocol was registered in July 2022 to the International Prospective Register of Systematic Reviews, PROSPERO (Registration Number: CRD42022350068).

2.1 Study eligibility

For studies to be included, they had to be peer-reviewed and written in English or with an English translation. To ensure a comprehensive analysis of the recorded prevalence rates of PTSD across all age groups, no age limit was applied. All previous and current diagnostic labels for autism were included, such as autism spectrum disorder (ASD), Asperger's syndrome, childhood autism, atypical autism, Kanner's syndrome, pervasive developmental disorder not otherwise specified (PDD-NOS), and childhood disintegrative disorder. The review only focused on research that used established diagnostic classifications from the International Classification of Diseases (ICD) or the Diagnostic and Statistical Manual for Mental Disorders (DSM) to diagnose autism. This included diagnoses made by a qualified healthcare professional or through a standardised diagnostic tool that adheres to ICD/DSM criteria. Similarly, the diagnosis of PTSD had to be established through diagnostic classification in the ICD/DSM by a qualified healthcare professional or through clinically significant scores on a standardised diagnostic tool that measures PTSD symptomatology.

Self-reported PTSD diagnoses were excluded if researchers or healthcare professionals did not confirm it.

The following studies were excluded from the review: non-primary research like book chapters, systematic reviews, grey literature, editorials, letters, conference abstracts, posters or case reports. Studies that combined PTSD with other disorders like 'anxiety or stress-related disorders' were also excluded as we could not be sure if the diagnoses was explicitly for PTSD. Studies that specifically recruited individuals with autism and a comorbid anxiety-related disorder were excluded as they could overestimate the recorded PTSD prevalence rates (Brady et al., 2000). Lastly, if more than one study used the same sample, only the study with the largest sample size was included. If the sample size was the same then the study with the most detailed sample characteristics was included.

2.2 Literature search

After consulting with a subject liaison librarian for bioscience and psychology, a systematic search was conducted on the following electronic databases: MEDLINE, Embase, Web of Science, PsychINFO, CINHAL Plus, and PTSDpubs (a PTSD-specific database). MEDLINE, Embase, and Web of Science were selected as they were recommended as the optimal combination of databases for systematic reviews (Bramer et al., 2017), while the others were included due to their relevance to mental health, autism, and psychiatric diagnoses such as PTSD. The search was limited to human studies published between January 1, 1980, and July 23, 2022, which was the date of the search. The start date was chosen as this was the year PTSD formally entered the psychiatric nosology through DSM-III (APA, 1980).

Two sets of search terms were employed in most databases, except Web of Science, which used (“autis*” and “traum*”). The first set of search terms included phrases associated with autism (“autis*” OR “ASD” OR “PDD*” OR “pervasive development* disorder*” OR “asperger*” OR “disintegrative disorder*” OR “kanner*”). The second set of search terms included phrases related to PTSD or psychiatric comorbidity, as some studies might have

PTSD prevalence rates within subanalysis when discussing psychiatric comorbidities ("post$traumatic stress*" OR "PTSD" OR "acute stress reaction" OR "stress disorder*" OR "traum*" OR "psychiatric comorbid*").

2.3 Study selection

All references and duplicates were initially managed using EndNote (Version 20) before being uploaded onto Rayyan, an open-source review management software (Ouzzani et al., 2016). The titles and abstracts of all studies were screened by one reviewer (HM), while a second reviewer (IA) randomly screened 10% of the studies. For full-text screening, both reviewers (HM and IA) independently screened each article against pre-established eligibility requirements, blinded from each other's selections. Inter-rater reliability showed almost perfect agreement (Kappa = 0.898; SE = 0.036; CI = 0.828-0.968), with discrepancies being discussed with a third reviewer (JS) until a consensus was reached (Landis & Koch, 1977). Where a publication could not be evaluated from the information in the title or abstract, it was moved into the full-text screening phase. Therefore, the exclusion of studies that might mention PTSD prevalence later in the main text was limited. Additional records were also identified by searching past systematic review reference lists (Kildahl et al., 2019; Lai et al., 2019; Lugo-Marin et al., 2019; Rumball, 2019; Ung et al., 2014; Vannuchhi et al., 2014). All citation and manual searches were completed by one reviewer (HM).

2.4 Data extraction

A standardised data form was developed so that two reviewers (HM and SK) could extract and cross-check data independently for all included full-text articles. Any differences were discussed and resolved by consensus with a third reviewer (JS). The data extracted included study information (authors, country, study design, and sampling methods), sample characteristics (age, gender, ethnicity, socioeconomic status, and level of cognitive functioning), autism diagnosis information (diagnostic criteria, assessment methods, sample size, and autism diagnosis composites), and PTSD-related factors (diagnostic criteria,

assessment methods, information source, prevalence type, prevalence rates, trauma type, and associated risk factors). As the primary focus of the review was on the recorded prevalence of PTSD within autism, studies were split into child-adolescent and adult populations based on the mean or median sample age.

Like a previous review by Rumball (2019), studies were categorised under the child-adolescent group if their mean or median sample age was 18 years or less. To distinguish between children and adolescents, 14 years of age or above was used as the cut-off age, as this has been used in other studies (Dube et al., 2006; Holly & Wittchen, 1998). Where both current and lifetime prevalence rates were reported, both were included and used for separate meta-analyses of current and lifetime PTSD prevalence. Prevalence estimates and confidence intervals were obtained by extracting the numerator and denominator. In cases where studies only reported percentages of PTSD diagnosis, the estimates were manually calculated, and missing data was requested from the study authors.

2.5 Risk of bias assessment

Study quality was assessed using the Newcastle-Ottaway Scale (NOS), with an adapted version being used for cross-sectional studies (Wells et al., 2000; Herzog et al., 2013). The NOS is a reliable and useful risk-of-bias (RoB) tool recommended by the Cochrane Collaboration for systematic reviews and meta-analysis (Higgins et al., 2011). Due to the heterogeneity of study designs and review objectives, RoB tools should be modified and tailored to unique designs (Farrah et al., 2019). Two reviewers (SK and HM) independently evaluated all the studies, with discrepancies being resolved through discussion with a third reviewer (JS). The standard version of the NOS has eight items divided into three groups that examine study groups, comparability of study groups, and ascertainment of either exposure or outcome of interest for case-control or cohort studies, respectively. The maximum number of points awarded for case-control and cohort studies was nine, indicating higher quality. Each study was assigned an overall RoB rating (high risk: 0–3, medium risk: 4–6, low risk: 7–9 points) for both case-control and cohort designs.

The adapted version of the NOS for cross-sectional studies consists of three groups comprising seven items: evaluating the selection of study groups, comparability of study groups, and ascertainment of the outcome of interest. A maximum of 10 points can be awarded for a cross-sectional study, indicating higher quality. For each cross-sectional study, an overall RoB rating (very good: 9-10, good: 7-8, satisfactory: 5-6, unsatisfactory: 0-4 points) was assigned. A breakdown of each RoB item and coding manuals can be found in Appendix 2a, 2b, and 2c. For case-control studies, the second item within the exposure domain states, "structured interview where blind to case/control status". Similarly, for cohort studies, the first item within the outcome domain states "independent blind assessment". A point was allocated for each criterion met.

While the NOS offers several advantages, such as being quick to implement, adaptable, and validated for case-control and longitudinal studies, it lacks a comprehensive manual, and there can be issues with inter-rater reliability as some scoring criteria items need to be adapted based on the review question (Luchini et al., 2017). For example, due to the objectives of the current literature review, researchers do not need to be blind to the case/control status, so studies using a structured interview or independent assessment/interview without blind researcher status received a point. Moreover, in line with other meta-analysis reviews, all studies were included in the final meta-analysis regardless of overall RoB scores (Lai et al., 2019; Varcin et al., 2022). This reduces the opportunity for selection bias, with additional statistical analysis also being used to check for outlier studies and publication bias.

2.6 Synthesis of the results

All prevalence estimates were statistically analysed in R (Version 4.2.2) using the *meta*, *metafor, tidyverse,* and *dmetar* packages (https://www.r-project.org/). To determine the pooled prevalence rate of PTSD among autistic child-adolescent and adult populations, a meta-analysis was conducted using a random-effects model (Bell et al., 2019). Pooled estimates for lifetime and current prevalence were calculated using double arcsine transformation to adjust

for non-normally distributed raw proportions that fall outside the range of 0.2 to 0.8 (Barendregt et al., 2013). The Egger weighted regression was used to calculate publication bias, with a funnel plot being used to visualise the detection of bias by the extent of asymmetry (Egger et al., 1997).

Heterogeneity was assessed using the I^2 statistic, with Cochran's Q test p-value being used to determine significance. As such, an I^2 value of 0% indicates no heterogeneity, whereas 25%, 50%, and 75% indicate low, moderate, and high heterogeneity, respectively (Borenstein et al., 2017). In the case of moderate-to-high heterogeneity, an outlier analysis was conducted to determine the influence of outliers on the pooled estimates and 95% confidence intervals (Viechtbauer & Cheung, 2010).

Subgroup analyses were also conducted with outliers removed to investigate other sources of heterogeneity and the impact of external factors (Song et al., 2001). This allowed a tentative exploration of the influence of various factors such as country region, study type, sampling source, gender, ethnicity, presence of intellectual disability, PTSD diagnostic criteria, and PTSD assessment method on overall prevalence rates. Since most studies featured a predominantly White male sample, ethnicity and gender were split using the median. Similarly, due to limited data on participants' level of functioning, studies were divided into those that included participants with intellectual disabilities and those that did not.

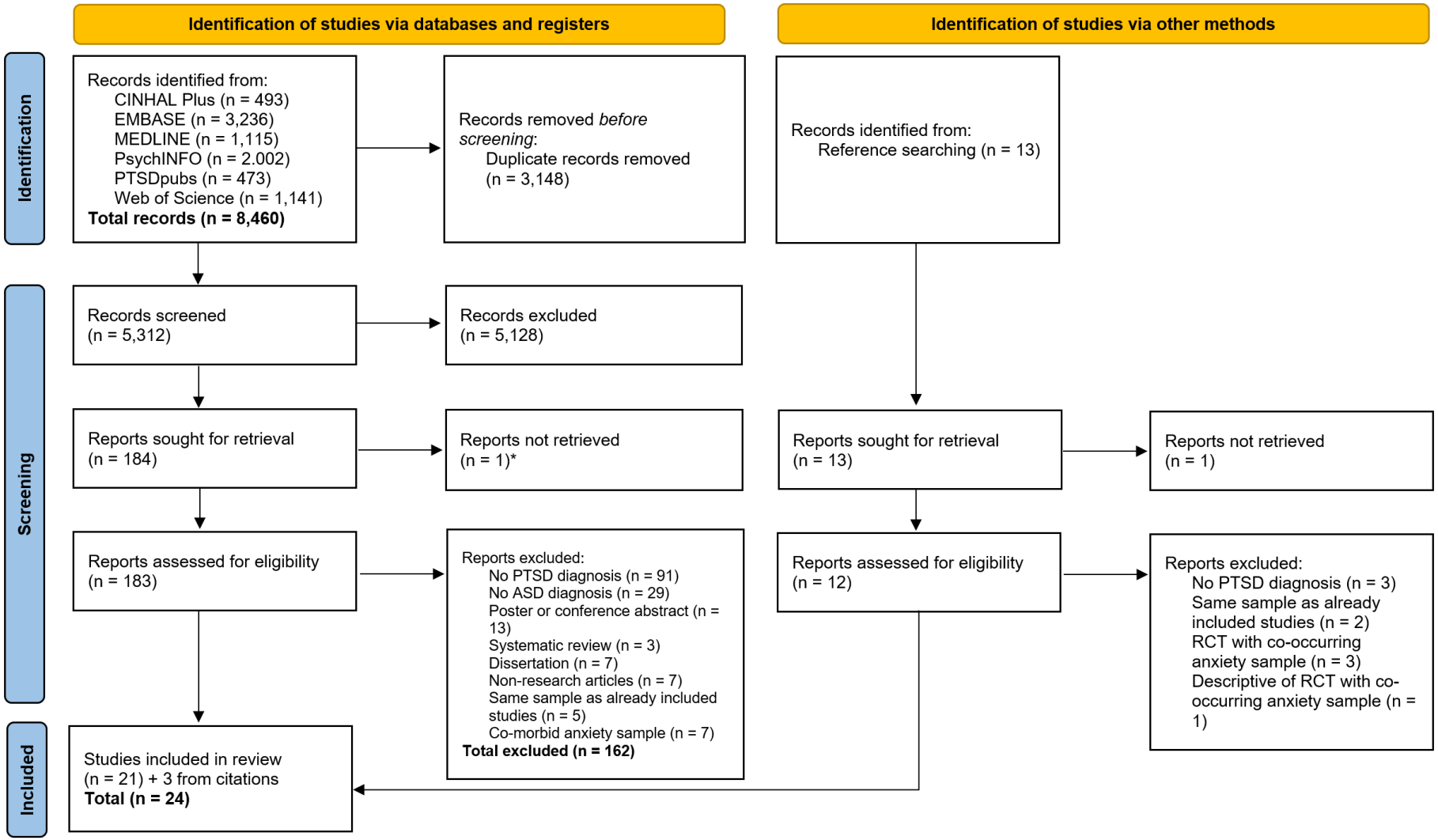
3. Results

3.1 Study selection

The literature search across six databases produced 8,460 records, with a further 13 records being identified through other sources, including citation searching and reviewing studies found in other systematic reviews. After removing 3,148 duplicates, 5,312 records were reviewed at the title and abstract stage. Five authors were contacted for full-text versions of their studies, with two excluded as no response was received (Broquere et al., 2016; Strunz et al., 2013). In total, 183 records were retrieved for full-text screening, and 24 studies were

included in the final data synthesis. A detailed breakdown of study selection can be seen in Figure 1 PRISMA flow diagram.

Figure 1. ***PRISMA flow diagram showing study selection***



* Broquere, M., Soussana, M., Michelon, C., Rattaz, C., Brisot, J., & Baghdadli, A. (2016). Impact of anxiety disorders on quality of life of adolescents with autism spectrum disorder without intellectual disability. L'encephale, 42(6), 499-505.
**Strunz, S., Dziobek, I., & Roepke, S. (2013). Comorbid psychiatric disorders and differential diagnosis of patients with autism spectrum disorder without intellectual disability. *Psychotherapie, Psychosomatik, Medizinische Psychologie*, *64*(6), 206-213.

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71. For more information, visit: http://www.prisma-statement.org/

3.2 Study characteristics

Out of the 24 included studies, 14 were categorised as child-adolescent studies with 6,044 autistic participants, and the remaining 10 were categorised as adult studies with 5,140 autistic participants. In total, 11,184 autistic participants with an official autism diagnosis were included in the meta-analysis.

The ASC sample size for the child-adolescent study category varied from 40 to 4,306 (median n = 69). Publication years ranged from 2008 to 2019, with seven studies (50%) conducted in North America, four (29%) in Europe, and one (7%) in Australia, Japan, and Turkey, respectively. Among the included studies, six (43%) were case-control designs, six (43%) were cross-sectional, and two (14%) were longitudinal. In terms of prevalence types, seven (50%) investigated current PTSD prevalence, four (29%) looked at lifetime prevalence, and three (21%) examined both current and lifetime prevalence. For further details, please see Table 1.

The ASC sample size for the adult study category varied from 36 to 4,049 (median n = 63). Publication years ranged from 2008 to 2020, with eight studies (80%) conducted in Europe and two (20%) in North America. Among the included studies, six (60%) were case-control designs, three (30%) were cross-sectional, and one (10%) was longitudinal. In terms of prevalence types, one study (10%) investigated the current PTSD prevalence, eight (80%) looked at lifetime prevalence, and one (10%) investigated both current and lifetime prevalence. For further details, please see Table 2.

3.3 Risk of bias assessment

Of the 24 total studies included, 12 (50%) were case-control, four (17%) were cohort, and eight (33%) were cross-sectional designs. Six (50%) of the 12 case-control studies had low RoB, whereas the remaining six (50%) had medium RoB. Three (75%) of the four cohort studies had medium RoB, and one (25%) had high RoB. Finally, seven (87.5%) of the eight cross-sectional studies were rated good, and one (12.5%) was rated unsatisfactory. However,

some domains of the NOS (e.g., selection and comparability) did not apply to specific cohort and cross-sectional studies (e.g., Gillberg et al., 2016; Roy et al., 2015) because of the need for a comparison group. As a result, the risk of bias for these studies should be interpreted with caution as it may overestimate a higher overall RoB, as studies were technically awarded no points for some items. For a detailed breakdown of RoB scoring, please see Appendix 3.

3.4 Participant characteristics

In the category of child-adolescent studies, the age of participants ranged from 3 to 21 years (median 11.6), with one study providing no age-related information. These studies were categorised into four groups based on the age range of participants: only child (k = 3), only adolescent (k = 1), child-adolescent (k = 9), and intermediate age (k = 1); the intermediate age range included participants up to 21 years old. Out of the nine studies that reported ethnicity, six had a sample with over 83.8% White participants, two had over 60.6% White, and one had 23% White. Regarding gender, the proportion of male participants in all studies ranged from 73.5 to 100% (median 80%). Ten studies provided information on the level of functioning, with the proportion of participants with an intellectual disability (IQ<70) ranging from 0 to 100% (median 20%). One study noted that a significant portion of its sample had intellectual disabilities without providing a specific numerical value. Regarding recruitment sources, eight studies recruited autistic participants from assessment or treatment referral sources, two used electronic hospital records (EHRs), two recruited primarily from the community, and two used a combination of community and referral sources. For more information, please see Table 1.

In the adult study category, the participants' ages ranged from 17.6 to 63 years (median 30). One study mentioned that all participants were over 18 years of age. Only three studies provided information on ethnicity, with one study stating that all participants were born in Sweden, and the others included predominantly (>91.7%) White ethnic background participants. Regarding gender, the proportion of male participants in all studies ranged from 50.9 to 100% (median 68%). Eight studies shared information on the level of functioning, with the proportion of participants having an intellectual disability (IQ<70) ranging from 0 to 28.2%

(median 0%). Seven studies recruited autistic participants from assessment or treatment referral sources; one used a register-based cohort database, and two used a combination of community and referral sources. For more information, please see Table 2.

3.5 Autism diagnostic criteria and assessment methods

Within the child-adolescent study category, the most frequently used autism diagnostic criteria was the DSM-IV (*k* = 4). Some studies also supplemented the DSM-IV with the research criteria for PDD-NOS (*k* = 2). Others used either the DSM-III or DSM-IV (*k* = 1), DSM-5 (*k* = 1), ICD-10 (*k* = 1), or the Collaborative Programs of Excellence in Autism (CPEA) diagnostic guidelines (*k* = 1). Four studies did not provide any information about autism diagnostic criteria. Throughout child-adolescent studies, the most frequently used autism assessment method was the Autism Diagnostic Observation Schedule (*k* = 7), which is a standardised semi-structured observational assessment used to assess autism (Lord et al., 2000). Other studies confirmed autism diagnosis through clinical interviews by trained professionals (*k* = 4), parent interviews and behavioural observations (*k* = 1), EHRs (*k* = 1), or the Childhood Autism Rating Scale (CARS; *k* = 1; Schopler et al., 2010). For more information, please see Table 1.

For the adult study category, the most frequently used diagnostic criteria for autism was the DSM-IV (*k* = 4). This was followed by a mixture of DSM-IV, ICD-9, or ICD-10 (*k* = 1), DSM-IV, or ICD-10 (*k* = 1), DSM-IV, ICD-10, Gillberg's criteria for Asperger's (*k* = 1), or ICD-10 (*k* = 1). Two studies did not provide any information about autism diagnostic criteria. For autism assessment methods, most studies used either the ADOS (*k* = 3) or a combination of neuropsychological assessment, developmental history, and clinical interview (*k* = 2). Other methods for confirming autism diagnosis included the use of a self-developed diagnostic interview for Asperger's in adulthood (*k* = 1), review of EHRs (*k* = 1), review of clinical records by secondary care practitioner (*k* = 1), CARS (*k* = 1), and the Asperger's Syndrome Diagnostic Interview (ASDI, *k* = 1; Gillberg et al., 2001). For more information, please see Table 2.

3.6 PTSD diagnostic criteria and assessment methods

For the child-adolescent study category, the most frequently used diagnostic criteria for PTSD was the DSM-IV (*k* = 7). Others used DSM-III or DSM-IV (*k* = 1), DSM-IV or ICD-10 (*k* = 1), DSM-IV, DSM-5, ICD-9, or ICD-10 (*k* = 1), and DSM-5 (*k* = 1). Three studies did not provide any information on PTSD diagnostic criteria. Concerning PTSD assessment methods, six studies used semi-structured interviews such as the Kiddie Schedule for Affective Disorders and Schizophrenia (K-SADS; *k* = 4; Kaufman et al., 1997), and the Structured Clinical Interview for DSM-IV Childhood Disorders (KID-SCID; *k* = 2; Hien et al., 1994). Others used the Child and Adolescent Psychiatric Assessment (CAPA; *k* = 1; Angold & Costello, 2000), the Diagnostic Interview Schedule for Children (DISC-IV; *k* =1; Shaffer et al., 2000), and the Diagnostic Interview for Children and Adolescents (DICA-IV; *k* = 1; Reich, 2000). The rest used the Child & Adolescent Symptom Inventory-5 behaviour rating scale (CASI-5; *k* = 2), the Development And Well-Being Assessment (DAWBA, *k* = 1; Goodman et al., 2000), and EHRs (*k* = 2). Most studies used parent responses (*k* = 9) to diagnose PTSD, with one of these studies supplementing parent responses with inpatient clinical observations. Three studies combined child and parent responses. However, the two EHR studies did not specify where the information for PTSD diagnosis came from. For more information, please see Table 3.

Within the adult study category, the most frequently used diagnostic criteria for PTSD was the DSM-IV (*k* = 7). Two studies used the ICD-10, and one reported no information on PTSD diagnostic criteria. Regarding PTSD assessment, the Structured Clinical Interview for DSM Disorders (SCID; *k* = 3; First & Gibbon, 2004) was the most popular method to obtain a diagnosis of PTSD. This was followed by the Mini-International Neuropsychiatric Interview (MINI; *k* = 2; Sheehan et al., 1998) and a review of EHRs (*k* = 2). Other PTSD diagnostic methods included the K-SADS (*k* = 1) and a clinical assessment or evaluation (*k* = 2). Most studies (*k* = 5) did not specify the source of information for PTSD diagnosis. However, four stated that PTSD diagnosis was based on self-report, and one of those also used parent

reports when available. Finally, one study only used parent reports for PTSD diagnosis. For more information, please see Table 4.

Table 1. ***Child and adolescent studies population characteristics***

Author (Year)	Country, Region	Study Type	Sampling source	Diagnostic criteria (ASD)	Assessment Instruments (ASD)	Total ASC N (Subtypes or Groups)	Total Control N	Age Mean (SD), Range	Sex (% Males)	Ethnicity (% White)	Level of Functioning (% IQ <70)
Bitsika and Sharpley (2014)	AUS, Queensland	CC	Recruited from local parent support groups and schools on the Gold Coast	DSM-V	2hr parent interview and a behavioural observation	140	Non-ASC: 50	ASC: 11.16 (3.30), 6-18	ASC: 140 (100%)	All Anglo-Saxon, with over 97% being born in Australia	100% of ASC participants had a FSIQ ≥70 (0% IQ <70)
Brenner et al. (2017)	USA	CS	Admissions into six inpatient speciality psychiatric hospital units with groups being split into those with and without reported abuse	NR	SCQ and ADOS-2	350 PTSD assessment was only administered to abuse reported ASC group (n = 99)	No reported abuse ASC group (n = 251)	Reported abuse ASC group 12.88 (3.32), 4-21	Reported abuse ASC group: 73 (73.7%)	Reported abuse group 67 non-Hispanic/Latino (94.4%)	58% scored above the clinical cut-off for ID (42% IQ <70)
Mansour et al. (2017)	USA	CS	Recruited from the general community, special education programs, special needs schools, community clinics, and parent advocacy groups	DSM-IV-TR	SCQ, ADI-R, and ADOS	99 (AD = 60; AS = 18; PDD-NOS = 21)	NA	9.37 (1.8), 6.7–13.5	78 (78.8%)	60 were Caucasian (60.6%)	FSIQ ranged from 46-128 (NR)
Reinvall et al. (2016)	FIN, Helsinki	CC	Participants were recruited from the department of child neurology, and a private neurorehabilitation centre	ICD-10	CI by child neurology or MDT team, and ADI-R	60 (AS = 60)	TD Controls = 60	AS group: 11.6 (2.5)	AS group: 48 (80%)	NR	100% of AS group had FSIQ above 70 (0% IQ <70)
Plesa Skwerer et al., 2019)	USA	CS	Recruited from a variety of resources in the community, including schools, clinics, and social media	NR	A-ADOS-1, ADOS-2, ADI-R	65 (Minimally verbal children = 33; Minimally verbal adolescents = 32)	NA	Children: 7.59 (1.99), 5-11 Adolescents: 14.79 (1.9), 12-18	Children: 27 (82%) Adolescents: 22 (69%)	Children: 60.6% Adolescents: 68.8%	Minimally verbal ASC sample (100% IQ <70)
van Steensel et al. (2012)	NLD, Maastricht	CC	Referrals into a general outpatient mental health centre	DSM-IV-TR	ADI-R, CI, and MDT consensus	ASC: 40 (AS = 12; PDD-NOS = 28)	ADHD = 40	ASC: 11.10 (2.82), 8-18	ASC: 36 (90%)	NR	ASC: 80% had FSIQ above 70 (20% IQ <70)
Hollocks et al. (2016)	GBR, London	CC	ASC participants were recruited from NHS clinics. ASC group was then split into non-anxiety and co-occurring anxiety ASC groups	NR	ADOS and ADI-R, or SCQ and CI with a psychiatrist or psychologist	55 (34 with co-occurring anxiety; 21 without anxiety)	TD Control = 28	ASC anxiety: 12.8 (1.9), 10-16 ASC: 13 (1.9), 10-16	ASC: 55 (100%)	NR	ASC: 100% had FSIQ above 70 (0% IQ <70)

Bryson et al. (2008)	USA, Kansas	CS	One year's worth (2004) of electronic health record data from 26 community mental health centres	DSM-IV-TR	Electronic Health Records	586 (Autism = 107; Other ASC, which include AS, RD, or PDD-NOS = 479)	NA	Children with Autism 9.18 Children with other ASC 9.53	All: 495 (84.5%)	Children with autism: 81.9% Children with other ASC: 85.7%	NR, but the authors stated that a sizeable portion had ID
Hoch and Youssef (2019)	USA, Minnesota	CC	Children were seen by a community mental health provider between August 2013 and February 2018	NR	ADOS, ASRS, CBC, and VABS	ASC = 4306 ASC and DD = 660	DD = 236 Other MH condition = 2432	NR	(77.4%)	23% White with 91% having English as main language	NR
Mehtar and Mukaddes (2011)	TUR, Istanbul	LNG	Patients at the ASC clinic in the child-adolescent psychiatry department followed up for 1-12 years.	DSM-IV-TR	CARS and detailed medical examination	69 (AD = 59; AS = 5; PDD-NOS = 5)	NA	11.7 (3.3), 6-18	53 (76.8%)	NR	FSIQ between 70-135: 27.5% (72.5% IQ < 70)
Verheij et al. (2015)	NLD, Rotterdam	LNG	Diagnostic referrals to the department of child and adolescent psychiatry from July 2002 to September 2004	DSM-IV Research Criteria for PDD-NOS	ADOS-G	T1: 99 T2: 74 (PDD-NOS)	NA	T1: 9.02 (1.81), 6–12 T2: 16.0 (1.92), 12-20	All: 65 (88%)	90.5% had Dutch nationality	Mean IQ was 93 (SD = 16.96)
Orinstein et al. (2015)	USA and Canada	CC	Recruited through media outlets (newspaper stories, radio interviews), private practices, and clinic referrals	CPEA diagnostic guidelines	Review of clinical records, ADOS	42 (HFA = 42)	OO = 33 TD = 34	HFA group 13.9 (2.7), 8.6-20	HFA: 38 (90.5%)	HFA: 40 (95.2%)	100% had FSIQ greater than 77 (0% IQ <70)
Joshi et al. (2014)	USA, Boston	CS	Referrals to either a specialist ambulator ASD clinic or a paediatric psycho-pharmacology clinic from October 2007 to March 2012	DSM-III-R, DSM-IV	CI with psychiatrist	360 (Ambulator clinic = 143; Paediatric clinic = 217)	NA	Ambulatory: 10 (3.8), 3-17 Paediatric: 9.7 (3.6), 3-17	Ambulatory: 125 (87%) Paediatric: 188 (87%)	Ambulatory Clinic: 124 (88%) Paediatric Clinic: 164 (93%)	Ambulatory Clinic: 91% Paediatric Clinic: 97% had FSIQ >70
Kusaka et al. (2014)	JPN, Osaka	CS	Referrals of patients receiving treatment at a psychiatry outpatient clinic between July 2007 and September 2010	DSM-IV-TR Research Criteria for PDD-NOS	CI with psychiatrist	49 (AD = 24; AS = 4; PDD-NOS = 21)	NA	11.2, 6-15	36 (73.5%)	NR	IQ <70 was an exclusion criteria (0% IQ <70)

Key: CC: Case Control; CS: Cross-Sectional, CS: Cohort Study; LNG: Longitudinal; DSM-V: The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition; NR: Not Reported or Not Relevant; SCQ: Social Communication Questionnaire; ADOS-2: Autism Diagnostic Observation Schedule, Second Edition; DSM-IV-TR: The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision; ADI-R: Autism Diagnostic Interview-Revised; ICD-10: The International Classification of Diseases, Tenth Revision; CI: Clinical Interview by child neurology or Multidisciplinary Team (MDT); A-ADOS-1: Autism Diagnostic Observation Schedule, First Edition; ADOS: Autism Diagnostic Observation Schedule; ASRS: Autism Screening Questionnaire; CBC: Child Behavior Checklist; VABS: Vineland Adaptive Behavior Scales; CARS: Childhood Autism Rating Scale; EHR: Electronic Health Records; ADOS-G: Autism Diagnostic Observation Schedule – Generic; CPEA: Collaborative Programs of Excellence in Autism for diagnosis; DSM-III-R: The Diagnostic and Statistical Manual of Mental Disorders, Third Edition, Revised; DSM-IV: The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition; ASC: Autism Spectrum Condition; TD: Typically Developing Control; ADHD: Attention Deficit Hyperactivity Disorder; OO: Optimal Outcome; MH: Mental Health Condition; DD: Developmental Disorder; FSIQ: Full-Scale Intelligence Quotient; IQ: Intelligence Quotient.

Table 2. ***Adult studies population characteristics***

Author (Year)	Country, Region	Study Type	Sampling source	Diagnostic criteria (ASD)	Assessment Instruments (ASD)	Total ASC N (Subtypes or Groups)	Total Control N	Age Mean (SD), Range	Sex (% Males)	Ethnicity (% White)	Level of Functioning (% IQ ≤70)
Russell et al. (2015)	GBR	CC	Retrospective case review of assessment referrals to the national specialist clinic for autism between April 2003 and September 2011	DSM-IV, ICD-10	ADOS and ADI-R	ASC: 474 (childhood autism = 115; AS = 212; atypical autism = 100; PDD-NOS = 47)	Non-ASC control: 385	ASC: 30.59 (11.18)	ASC: 372 (78.4%)	NR	ID was an exclusion criteria (0% IQ <70)
Gillberg et al. (2016)	SWE, Gothenburg	LNG	Assessment referrals into the child neuropsychiatric clinic between 1985-99 followed-up at T2 (2011-13)	DSM-IV, ICD-10, Gillberg's criteria for AS	CARS	T2: 50	NA	T2: 30.2 (5.0), 23-43	ASC: 50 (100%)	NR but all were born in Sweden	ID was an exclusion criteria (0% IQ <70)
Lever and Guerts (2016)	NLD	CC	Recruited through several mental health institutes and using adverts on client organisation websites	NR	ADOS Module 4	ASC: 138 (Young ASC = 46; Middle ASC = 47; Older ASD = 45)	Non-ASC: 170	ASC: 46.5 (Young 28.8; Middle 47.2; Older 63.9)	ASC: 96 (69.6%)	NR	ASC Mean IQ = 113.8 (NR)
Nimmo-Smith et al. (2020)	SWE, Stockholm	CC	Register-based cohort database of all individuals aged 18 or above who lived in Stockholm for at least 1-year between January 2001 and December 2011	DSM-IV, ICD-9, ICD-10	Electronic healthcare records via national and regional registers	ASC: 4,059 (ASC without ID = 2,908; ASC with ID = 1,141)	Non-ASC control: 217,645	ASC: 21.97 (2.71), 18-27 ASC without ID: 21.95 (2.68); ASC with ID: 22.04 (2.80)	ASC: 2,065 (50.9%)	NR	71.8% FSIQ ≥70 (28.2% IQ <70)
Roy et al. (2015)	DEU	CS	Assessment referrals to the outpatient clinic with clients either self-referring or being sent due to suspicion of AS	DSM-IV	Self-Developed Diagnostic Interview (AS in adulthood)	ASC: 50 (AS = 50)	NA	ASC: 36.5, 20-62	ASC: 34 (68%)	NR	NR
Rydén and Bejerot (2008)	SWE, Stockholm	CC	Specialist referrals to the neuropsychiatry unit, which is a tertiary psychiatric clinic	DSM-IV	Neuropsychological testing, developmental history, medical record review, and clinical consensus	ASC: 84	Neither ASC nor ADHD controls: 46	ASC: 30 (10)	ASC: 45 (54%)	NR	ID was an exclusion criteria (0% IQ <70)

Underwood et al. (2019)	GBR, Cardiff	CC	Recruited from primary, secondary, and tertiary healthcare services. As well as adverts in local media and voluntary organisations.	ICD-10	Review of clinical records confirmed by secondary care clinician	ASC: 105	Control: 76	Aged 18+	ASC: 79 (75%)	100% Caucasian	ID was an exclusion criteria (0% IQ <70)
Hofvander et al. (2009)	FRA and SWE, Paris and Gothenburg	CS	Assessment referrals into two specialist diagnostic centres focused on the neuropsychiatric assessment of childhood-onset disorders in adults.	DSM-IV, Gilberg's criteria	ASDI and clinical records	ASC: 122 (Paris group = 38; Gothenburg group = 83)	NA	ASC median age: 29, 18-60 (Paris: 25, 18-47; Gothenburg: 30, 19-60)	ASC: 82 (67%)	NR	ID was an exclusion criteria (0% IQ <70)
Taylor and Gotham (2016)	USA	CS?	Recruited through local clinics and other autism-related research studies. As well as local support groups, service providers, and autism organisations	NR	ADOS, ADI-R	36 (last year of high school)	NA	ASD group 18.7 (1.3), 17.6-22.0	All: 30 (83.3%)	91.7% white non-Hispanic	72.2% FSIQ $\geq$70 (27.8% IQ <70)
Joshi et al. (2013)	USA	CC	Referrals into a specialised ambulator program at a university hospital from October 2007 to March 2012	DSM-IV	Neuropsychological assessment, structured diagnostic and psychiatric interview	ASC: 63 (AD = 41; AS = 16; PDD-NOS = 6)	Non-ASC: 63	ASC: 29.2 (11), 18-63	ASC: 41 (65%)	ASC: 55 Caucasian (95%)	ASC: 97% FSIQ $\geq$70 (3% IQ <70)

Key: CC: Case Control; LNG: Longitudinal; CS: Cross-Sectional; CS: Cohort Study; DSM-IV: The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition; ICD-10: The International Classification of Diseases, Tenth Revision; ADOS: Autism Diagnostic Observation Schedule; ADI-R: Autism Diagnostic Interview-Revised; Gillberg's criteria for AS: Diagnostic criteria for Asperger Syndrome; CARS: Childhood Autism Rating Scale; NR: Not Reported; ADOS Module 4: Autism Diagnostic Observation Schedule Module 4; ICD-9: The International Classification of Diseases, Ninth Revision; ASDI: Autism Spectrum Disorder Interview; ID: Intellectual Disability: FSIQ: Full-Scale Intelligence Quotient: ? Unspecified in text

Table 3. ***Child and adolescent studies population PTSD outcomes***

Author (Year)	Country	Study Type	Population	Diagnostic criteria (PTSD)	Assessment (PTSD)	Respondent	Trauma Type	PTSD Prevalence Type and %	Risk of Bias
Bitsika and Sharpley (2015)	AUS, Queensland	CC	Child and adolescent	DSM-V	KID-SCID	Child and Parent (Parent)	NR	Current?: 2.1% (3/140)	Medium
Brenner et al. (2018)	USA	CS	Child and adolescent (Intermediate)	DSM-V	Inpatient team (child psychiatrist and unit clinician), CASI-5 with additional PTSD items	Inpatient Observation, Parent CASI	Abuse	Current?: 2% (7/99)	Good
Mansour et al. (2017)	USA	CS	Child	DSM-IV-TR	DICA-IV	Parent	NR	Current?: 0% (0/99)	Good
Reinvall et al. (2016)	FIN, Helsinki	CC	Child and adolescent	DSM-IV, ICD-10	DAWBA	Parent	NR	Current?: 1.7% (1/60)	Medium
(Plesa Skwerer et al., 2019)	USA	CS	Child and adolescent	NR	CASI-5	Parent	NR	Current Symptoms: 13.85% (9/65)	Good
van Steensel, Bogel, and Bruin (2013)	NLD, Maastricht	CC	Child and adolescent	DSM-IV	KID-SCID	Child and Parent (Combined)	NR	Current?: 0% (0/40)	Medium
Hollocks et al. (2016)	GBR, London	CC	Child and adolescent	NR	CAPA	Parent	NR	Current: 0% (0/55)	Medium
Bryson et al. (2008)	USA, Kansas	CS	Child (No range)	DSM-IV-TR	Electronic hospital records	NR	NR	Lifetime: 3.58% (21/586)	Medium
Hoch and Youssef (2020)	USA, Minnesota	CC	NR	DSM-IV, DSM-V, ICD-9, ICD-10	Electronic Hospital Records	NR	Living situations or negative life events	Lifetime?: 4.25% (183/4306)	Low

Mehtar and Mukaddes (2011)	TUR, Istanbul	LNG	Child and adolescent	DSM-IV	K-SADS-PL, with the PTSD scale being applied to trauma-exposed individuals	Child and Parent (Combined)	Criterion A Traumas	Lifetime: 17.39% (12/69)	Medium
Verheij et al. (2015)	NLD, Rotterdam	LNG	Child and adolescent	DSM-IV-TR	DISC-IV-P	Parent	NR	Lifetime? T2: 1.35% (1/74)	Medium
Orinstein et al. (2015)	USA and Canada	CC	Child and adolescent (Intermediate)	DSM-IV	K-SADS-PL	Parent	NR	Current: 0% (0/42) Lifetime: 4.67% (2/42)	Low
Joshi et al. (2014)	USA, Boston	CS	Child and adolescent	DSM-III-R, DSM-IV	Diagnostic Interview, K-SADS-E	Parent	NR	Current: 1.1% (4/360) Lifetime: 2.5% (9/360)	Good
Kusaka et al. (2014)	JPN, Osaka	CS	Child and adolescent	DSM-IV-TR	K-SADS-PL-J	Parent	NR	Current: 2.04% (1/49) Lifetime: 2.04% (1/49)	Good

Key: DSM-V: The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition; KID-SCID: Kiddie Schedule for Affective Disorders and Schizophrenia - Present and Lifetime Version; DSM-IV-TR: The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision; DICA-IV: Diagnostic Interview for Children and Adolescents - Fourth Edition; ICD-10: The International Classification of Diseases, Tenth Revision; DAWBA: Development and Well-Being Assessment; NR: Not Reported; CASI-5: Clinician-Administered PTSD Scale for Children and Adolescents - Fifth Edition; CAPA: Child and Adolescent Psychiatric Assessment; EHR: Electronic Hospital Records; K-SADS-PL: Kiddie Schedule for Affective Disorders and Schizophrenia - Present and Lifetime Version; DSM-III-R: The Diagnostic and Statistical Manual of Mental Disorders, Third Edition, Revised; K-SADS-E: Kiddie Schedule for Affective Disorders and Schizophrenia - Epidemiologic Version; K-SADS-PL-J: Kiddie Schedule for Affective Disorders and Schizophrenia - Present and Lifetime Version – Japanese Version: ? Unspecified in text

Table 4. *Adult studies population PTSD outcomes*

Author (Year)	Country	Study Type	Population	Diagnostic criteria (PTSD)	Assessment (PTSD)	Respondent	Trauma Type	PTSD Prevalence Type and %	Risk of Bias
Russell et al. (2016)	GBR	CC	Adult	NR	Clinical Assessment	NR	NR	Current?: 0.4% (2/474)	Low
Gillberg et al. (2016)	SWE, Gothenburg	LNG	Adult	DSM-IV	MINI	NR	NR	Lifetime?: 0% (0/50)	High
Lever and Guerts (2016)	NLD	CC	Adult	DSM-IV	MINI	Self	NR	Lifetime: 2.9% (4/138)	Medium
Nimmo-Smith et al. (2020)	SWE, Stockholm	CC	Adult	ICD-10	Electronic Hospital Records	NR	NR	Lifetime: 0.74% (30/4049)	Low
Roy et al. (2015)	DEU	CS	Adult	DSM-IV	SCID-I (German Version)	Self?	NR	Lifetime: 2% (1/50)	Unsatisfactory
Rydén and Bejerot (2008)	SWE, Stockholm	CC	Adult	DSM-IV	Clinical evaluation taking 12-18 hrs to complete	NR	NR	Lifetime: 1.9% (1/53)	Medium
Underwood et al. (2019)	GBR, Cardiff	CC	Adult (No Age Range)	ICD-10	Electronic Hospital Records	NR	NR	Lifetime: 5.7% (6/105)	Low
Hofvander et al. (2009)	FRA and SWE, Paris and Gothenburg	CS	Adolescent and adult (Intermediate)	DSM-IV	SCID and clinical interview	Self?	NR	Lifetime: 1.6% (2/122)	Good
Taylor and Gotham (2016)	USA	CS?	Adolescent and adult (Intermediate)	DSM-IV	K-SADS-PL	Parent	NR	Lifetime: 0% (0/36)	Good
Joshi et al. (2013)	USA	CC	Adult	DSM-IV	SCID	Self and Parent when available	NR	Current: 4.8% (3/63) Lifetime: 11.1% (7/63)	Low

Key: NR: Not Reported; DSM-IV: The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition; MINI: The Mini International Neuropsychiatric Interview; ICD-10: The International Classification of Diseases, Tenth Revision; EHR: Electronic Hospital Records; SCID-I (German Version): The Structured Clinical Interview for DSM Disorders - I (German Version); SCID: The Structured Clinical Interview for DSM Disorders; K-SADS-PL: The Kiddie Schedule for Affective Disorders and Schizophrenia - Present and Lifetime Version: ? Unspecified in text

3.7 PTSD prevalence rates in child-adolescent studies

Ten studies involving 1,009 child-adolescent participants investigated the co-occurrence of current PTSD diagnosis in autism. The recorded PTSD diagnosis rate across all studies ranged from 0.0000 to 0.1385. As shown in Figure 2, Panel A, the pooled proportion of current PTSD diagnoses in autism was 0.0148 (95%CI = 0.0049; 0.0434, t^2 = 1.5271). This translates into a pooled current PTSD prevalence rate of 1.48% (95%CI = 0.49; 4.34%, t^2 = 1.5271) across all child-adolescent studies. However, these results should be treated with caution since there was moderate heterogeneity (Q = 38.52, df = 9, I^2 = 63.0%, p < .0001), and there was evidence of publication bias (Egger's t = -2.645, p = 0.029482). In addition, asymmetry was observed in the funnel plot (Appendix 4a), with outlier analysis identifying one outlier (Plesa Skwerer et al., 2019). After removing this study, the pooled prevalence rate of current PTSD diagnosis declined slightly to 0.0125 (95%CI = 0.0047; 0.0324, t^2 = 0.6927) or 1.25% (95%CI = 0.47; 3.24) and the level of heterogeneity was reduced to low (Q = 18.74, df = 8, I^2 = 21.4%, p = 0.016).

Subgroup analyses highlighted significant differences in current PTSD proportion rates according to the PTSD assessment method (Q = 11.63, p = 0.04). The proportion of current PTSD diagnoses was notably higher for CASI-5 (0.0707, 95%CI = 0.0341; 0.1410) than for KID-SCID (0.0167, 95%CI = 0.0054; 0.0504), DICA-IV (0.0000. 95%CI = 0.0000; 1.0000), DAWBA (0.0167, 95%CI = 0.0023; 0.1090), CAPA (0000. 95%CI = 0.0000; 1.0000), and K-SADS (0.0111, 95%CI = 0.0046; 0.0264). However, this result should be taken with caution because only one child-adolescent subgroup analysis study used the CASI-5. For a detailed breakdown of the subgroup analysis results, please see Appendix 4b.

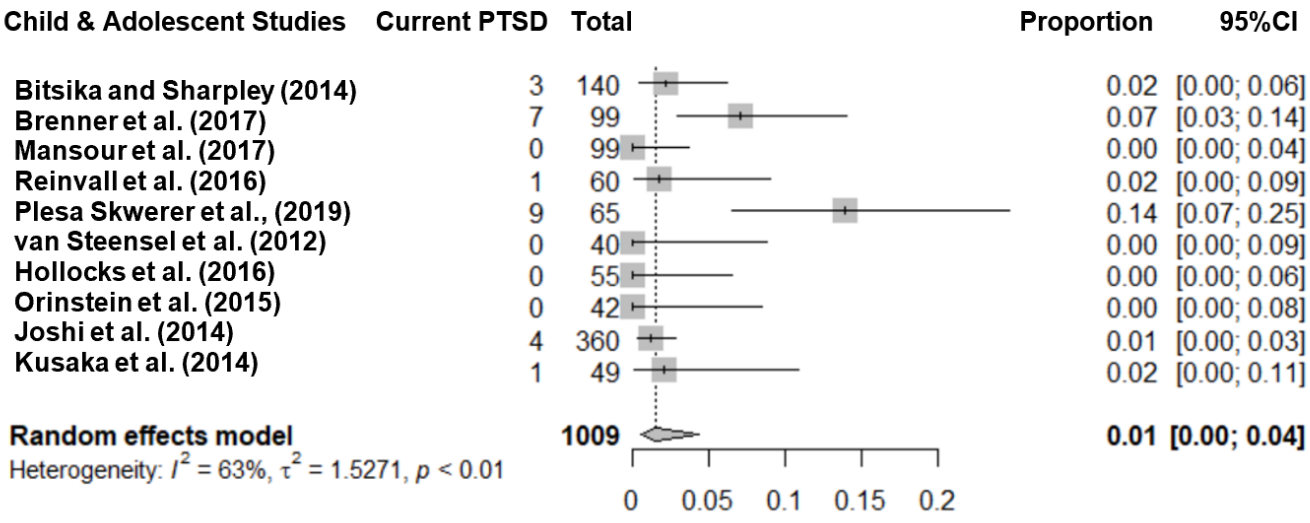
Seven studies involving 5,486 autistic child-adolescent participants investigated the co-occurrence of lifetime PTSD diagnoses in autism. The recorded PTSD prevalence rate across studies ranged from 0.0135 to 0.1739. The pooled proportion of lifetime PTSD diagnoses in autism was 0.0404 (95%CI = 0.0225; 0.0716, t^2 = 0.4397), as shown in Figure 2, Panel B. This translates into a pooled lifetime PTSD prevalence rate of 4.04% (95%CI = 2.25;

7.16, $t^2 = 0.4397$) across all child-adolescent studies. However, these results need to be taken with caution as heterogeneity was high (Q = 23.56, df = 6, $I^2 = 79.4\%$, p = 0.0006), but there was no evidence of publication bias (Egger's t = -2.48, p = 0.9904165). Asymmetry was further observed by the funnel plot (Appendix 5a), with outlier analysis identifying one outlier (Mehtar & Mukaddes, 2011). Removal of this study did not significantly change the pooled proportion rate of lifetime PTSD diagnosis, which reduced only slightly to 0.0401 (95%CI = 0.0352; 0.0456, $t^2 = 0$) or 4.01% (95%CI = 3.52; 4.56). However, it reduced the levels of heterogeneity to zero (Q = 5.84, df = 5, $I^2 = 0.0\%$, p = 0.3220).

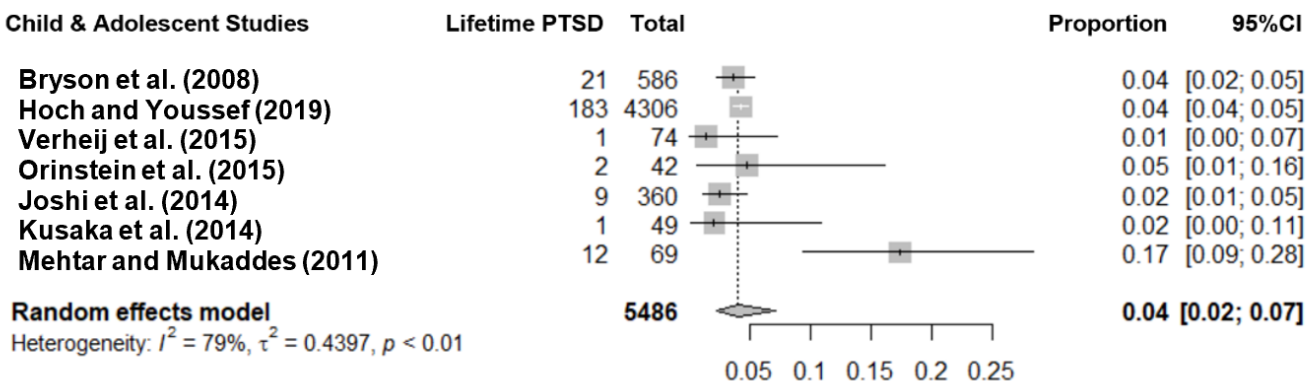
Subgroup analysis revealed no significant subgroup differences in child-adolescent lifetime PTSD proportion rates. For a detailed breakdown of the subgroup analysis results, please see Appendix 5b.

Figure 2. Forest plots of child and adolescent studies for (A) current and (B) lifetime pooled PTSD proportions

(A)



(B)



3.8 PTSD prevalence rates in adult studies

Two studies involving 537 autistic adult participants investigated the co-occurrence of current PTSD diagnosis in autism. The recorded PTSD prevalence rate across studies ranged from 0.0042 to 0.0476. Figure 3, Panel A shows that the pooled proportion of current PTSD diagnoses in autism was 0.0125 (95%CI = 0.0022; 0.0677, t^2 = 1.1280). This translates into a current PTSD prevalence rate of 1.25% (95%CI = 0.22; 6.77, t^2 = 1.128) across all adult studies. However, these results should be taken with caution as heterogeneity was high (Q = 6.73, df = 1, I^2 = 86%, p = .0095), and it was not possible to conduct an Egger's test for publication bias because there were only two studies. Moreover, although the funnel plot (Appendix 6) and further analysis indicate no outliers, this should be interpreted cautiously because only two studies were included in the meta-analysis. Therefore, no exploratory subgroup analysis was conducted for current PTSD prevalence in adult studies.

Nine studies involving 4,666 autistic adult participants investigated the co-occurrence of lifetime PTSD diagnosis in autism. The reported PTSD proportion rate across studies ranged from 0.0000 to 0.1111. Figure 3, Panel B shows that the pooled proportion of lifetime PTSD diagnoses in autism was 0.0200 (95%CI = 0.0094; 0.0423, t^2 = 0.7944). This translates into a pooled lifetime PTSD prevalence rate of 2.00% (95%CI = 0.94; 4.23, t^2 = 0.7944) across all adult studies. However, these results should be interpreted with caution, as heterogeneity was high (Q = 41.72, df = 8, I^2 = 85.5%, p < .0001). Although there was no evidence for publication bias (Egger's t = 1.151, p = 0.2875), the funnel plot (Appendix 7a) and further analysis suggest the presence of one outlier study (Joshi et al., 2013). Removal of this study reduced the pooled proportion of lifetime PTSD diagnoses to 0.0154 (95%CI = 0.0078; 0.0302, t^2 = 0.4194) or 1.54% (95%CI = 0.78; 3.02), but heterogeneity remained moderate to high (Q = 20.38, df = 7, I^2 = 72.5%, p = .0048).

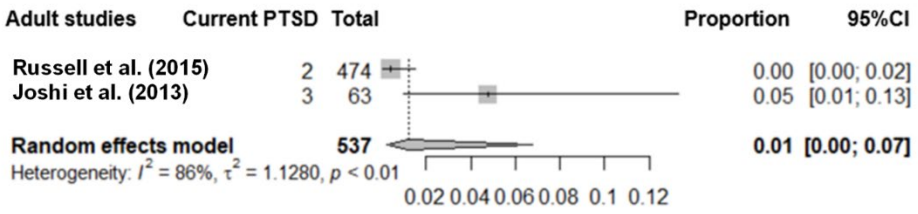
Subgroup analyses highlighted significant differences in lifetime PTSD proportion rates according to sampling source (Q = 9.29, p = 0.01), gender (Q = 4.79, p=0.03), ethnicity (Q = 5.85, p = 0.02), and presence of intellectual disability (Q = 10.55, p = 0.005). Findings suggest

studies that used assessment or treatment referrals (0.0237, 95% CI = 0.0100; 0.0552), or a mixture of referral and community sampling sources (0.0230, 95%CI = 0.0087; 0.0596), had significantly higher PTSD prevalence rates than those that used a register-based cohort as a sampling source (0.0074, 95%CI = 0.0052; 0.0106). Similarly, studies with more male participants (> 68%) had significantly higher PTSD proportion rates (0.0275, 95%CI = 0.0095; 0.0766), compared to those with fewer male participants (≤ 68%) in the sample (0.0080, 95%CI = 0.0057; 0.0111). Although most studies did not report information on ethnicity (k = 6), it would appear that studies with a majority white sample (> 90%) had significantly higher PTSD proportion rates (0.0426, 95% CI = 0.0192; 0.0915) than those that did not report data on ethnicity (0.0113, 95% CI = 0.0054; 0.0233). Finally, studies that excluded intellectual disability (0.0236, 95%CI = 0.0087; 0.0622) or did not report on intellectual disability (0.0266, 95%CI = 0.0111; 0.0623) had significantly higher recorded PTSD prevalence rates, compared to studies that included co-occurring intellectual disability (0.0073, 95% CI = 0.0051; 0.0105). For a detailed breakdown of the subgroup analysis results, please see Appendix 7b.

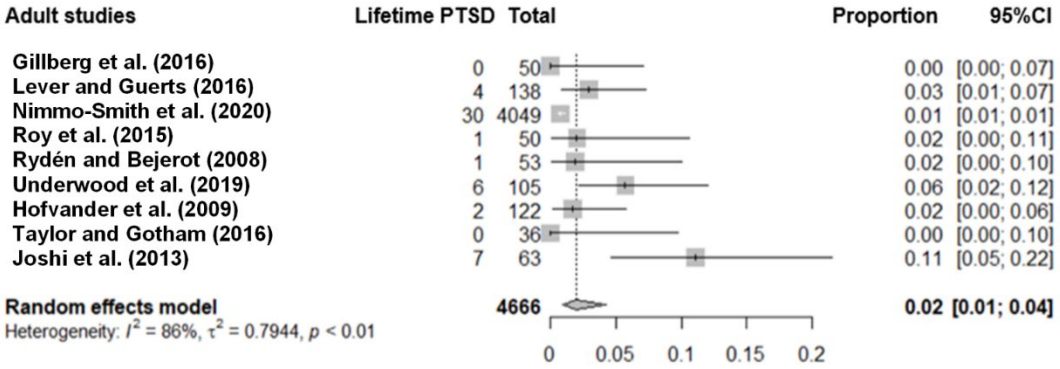
Please note that two studies were included in the adult meta-analysis rated as having either a high or unsatisfactory risk of bias (Gillberg et al., 2016; Roy et al., 2015). These ratings were obtained as neither study recruited a representative sample, the cohort study did not include a comparison group, and neither study controlled for confounders, with one study not describing any of the statistical tests used. This means that the overall findings from these studies might be due to selection bias. However, as stated in the risk of bias results section, there is a possibility that the reviewers might have overestimated the overall level of risk as the current review's objectives can be met without a control group. As such, included studies do not necessarily require a control group, but the NOS requires these criteria to be rated. Thus, whilst these criteria might not apply to all studies, the reviewers still had to score the criteria as zero, potentially overestimating the risk of bias.

Figure 3. Forest plots of adult studies for (A) current and (B) lifetime pooled PTSD proportions

(A)



(B)



4. Discussion

The current review explored recorded PTSD prevalence rates among diagnosed autistic populations. This was examined by collecting current and lifetime PTSD prevalence rates from 14 child-adolescent and 10 adult studies. In addition, subgroup analyses explored the impact of factors such as country region, study type, sampling source, gender, ethnicity, presence of intellectual disability, PTSD diagnostic criteria, and assessment method on the overall recorded PTSD prevalence rates.

4.1 Child and adolescent prevalence rates

Meta-analysis without any outlier studies suggests that the current recorded PTSD prevalence within diagnosed autistic child-adolescent studies is 1.25%, with a lifetime prevalence of 4.01%. These figures differ from those of a previous review by Rumball (2019), which reported a current prevalence of 2.85% from eight studies and a lifetime prevalence of 17.4% from just one study. However, that review did not conduct a meta-analysis or control for outliers. Although rates are lower than those reported in the previous review, they remain within the PTSD prevalence range observed in the general population. Studies on neurotypical child-adolescent populations suggest a current PTSD prevalence range of 0.6 to 3.9% and a lifetime prevalence range of 1.3 to 7.8% (Breslau et al., 2006; McLaughlin et al., 2013; Perkonigg et al., 2000). As such, findings could suggest that core features associated with autism do not increase or decrease the likelihood of developing PTSD.

However, the relationship between autism and PTSD is complex, and clinicians may miss PTSD diagnoses in autistic children and adolescents because of pre-existing emotional or behavioural symptoms (Brenner et al., 2017). This is somewhat supported by subgroup analysis of child-adolescent current recorded PTSD diagnoses, where the type of assessment method influenced the overall recorded prevalence rates. Findings also suggest that the CASI-5 plus inpatient observations produced a significantly higher PTSD prevalence rate than other methods. This might be because the CASI-5 plus inpatient observations focus on symptom

severity, so clinicians might want to focus on this when assessing PTSD in autistic children or adolescents. This finding is based on a single study, so further research is needed to confirm it. However, it is worth noting that one outlier study (Plesa Skwerer et al., 2019) also used the CASI-5 and found higher prevalence rates. Subgroup analysis of child-adolescent lifetime recorded PTSD prevalence found no significant subgroup differences.

4.2 Adult prevalence rates

Based on this meta-analysis, the current recorded prevalence of PTSD in diagnosed autistic adults is 1.25%. After removing one outlier, the lifetime recorded prevalence of PTSD was 1.54%. This estimate is higher than the mean lifetime PTSD prevalence of 0.8% found in the only other review that examined PTSD assessment and treatment in autism (Rumball, 2019). However, the previous review was based on only two adult studies and did not conduct a meta-analysis. Notably, although the pooled prevalence rates are higher than those reported in the other review, they fall short of those observed in the general population. The World Health Organisation World Mental Health Surveys found a 12-month current prevalence of 2.8% and a lifetime prevalence of 3.9% across 26 countries (Koenen et al., 2017). Moreover, most studies included in the meta-analysis were from higher-income countries, which should produce higher PTSD prevalence rates (Koenen et al., 2017).

The meta-analysis results are also significantly lower than studies that examined post-traumatic symptomology in self-reported or high autistic trait populations (Stewart et al., 2022; Haruvi-Lamdan et al., 2020). These studies found a 10 and 12-fold increase in the likelihood of the autism group having symptoms that meet the clinical cut-off for probable PTSD. Similarly, a recent UK-based study found that individuals who self-report as having an autism diagnosis have higher probable PTSD rates (32%) than age- and gender-matched neurotypical controls (4%; Rumball et al., 2021). Therefore, it is possible that findings only reflect recorded PTSD prevalence rates and not the rate of trauma within autistic populations. Moreover, if the lower rates observed in the review were due to underlying mechanisms of autistic traits preventing the development of PTSD, then similar prevalence rates would be

expected across all age groups, including child-adolescent studies. This suggests that stringent diagnostic criteria for trauma may contribute to an underestimation of PTSD prevalence rates, especially among autistic adult populations (Haruvi-Lamdan et al., 2020; Weathers & Keane, 2007).

Because only two studies were included in the current PTSD prevalence meta-analysis, it was not possible to conduct any subgroup comparisons. However, subgroup analysis of lifetime prevalence adult studies found that sampling source, gender, ethnicity, and presence of ID all influenced recorded prevalence rates. The one study that used a register-based cohort database had significantly lower PTSD prevalence rates when compared to referrals or combination referrals and community sampling methods. This might be due to a lack of guidance and consistency in recording diagnostic labels within clinical records (Shah et al. et al., 2019). Similarly, factors such as diagnostic overshadowing might mean that diagnoses are rare as autistic adults may struggle to self-report emotional or traumatic difficulties, and clinicians might assume PTSD symptoms are just part of the person's autism (Ben Shalom et al., 2006; Haruvi-Lamdan et al., 2018; Mazefsky et al., 2011). This could also explain why the overall pooled lifetime prevalence rate was higher in child-adolescent studies where parents were also interviewed during PTSD assessment. In this case, it might be helpful for clinicians to include information from close family members or friends when assessing PTSD.

Interestingly, studies with a higher proportion of male participants (>68%) and a larger proportion of individuals from white ethnic backgrounds (>90%) produced higher recorded lifetime PTSD prevalences, which is contrary to what has been observed in the general population. Females and those from ethnic minority backgrounds usually have a higher lifetime prevalence of PTSD (Alegría et al., 2013; Shalev et al., 2019). However, it should be noted that most studies in this subgroup analysis did not report information on ethnicity, making it difficult to determine the ethnic diversity of the samples. In addition, selection bias may exist because females and individuals from ethnic minority backgrounds are less likely to receive

an autism diagnosis, particularly in adulthood (Sedgewick et al., 2020; Tromans et al., 2020). This is particularly relevant to autistic females without a co-occurring intellectual disability, who might remain under-identified within previous autism diagnostic criteria as they display an increased prevalence of internalising difficulties and reduced stereotyped or repetitive behaviours (Kreiser & White, 2014).

Finally, subgroup analysis revealed significant differences in prevalence rates between samples that included individuals with intellectual disability and those that excluded or did not report any information about intellectual disability. This contrasts with what has been observed in the general population, where co-occurring intellectual disability is linked with higher PTSD prevalence rates (Daveney et al., 2019). However, the presence of intellectual disability in the subgroup analysis does not equate to severity. This is important because individual differences in cognitive abilities can impact traditional diagnostic methods, which rely heavily on verbal skills (Scott & Havercamp, 2018). As such, autistic adults with mild or moderate co-occurring intellectual disability may experience difficulties in accessing services or completing PTSD assessments without support. Similarly, evidence suggests that PTSD symptoms might manifest differently in people with co-occurring intellectual disability and may vary according to the level of severity (McNally et al., 2021; Mevissen & de Jongh, 2010). For example, symptoms can be mislabeled as ’behaviours of concern’ rather than PTSD (Rittmannsberger et al., 2020).

4.3 Strengths and limitations

This is the first review to calculate the pooled recorded prevalence rates of PTSD among diagnosed autistic child-adolescent and adult populations. By including studies that only recruited diagnosed autistic individuals, the review can be more confident that findings are specific to autism. However, this might also have introduced selection bias as various factors can prevent autistic individuals and their families from obtaining an official diagnosis (Huang et al., 2020; Bivarchi et al., 2021). Consequently, by only including diagnosed autistic individuals, the findings may not be generalisable to the entire autistic population, many of

whom remain undiagnosed. Similarly, by only including studies that utilised the "gold-standard" criteria for PTSD, the review can have confidence that individuals have received an official PTSD diagnosis based on established diagnostic criteria. However, this might not capture the actual rates of post-traumatic symptoms or experiences within autistic populations. This is important when considering that non-Criterion A traumas, such as adverse social events or victimisation, can lead to PTSD in autistic populations but may be overlooked by current diagnostic criteria (Brewin et al., 2009; Brewin et al., 2019; Haruvi-Lamdan et al., 2020).

Furthermore, the accuracy of the recorded PTSD prevalence rates depends on the quality and consistency of the assessment methods used. For example, four studies in the child-adolescent category used the K-SADS-PL with three basing PTSD diagnoses on parent responses, while one combined both parent and child responses. Similarly, four studies across both the child-adolescent and adult categories used EHRs to identify PTSD. While obtaining a diagnosis from EHRs can mean that a healthcare professional has confirmed the diagnosis, we cannot be sure what assessment method was used or if previous PTSD diagnoses were being accurately recorded. For instance, some studies have found that psychiatric diagnoses such as PTSD or severe mental illness might be more likely to be missed from EHR if an individual has less severe symptoms or if they are from an ethnic minority background (Morgan et al., 2019; Mansour et al., 2020). Despite this, the overall quality and robustness of the studies included in the meta-analysis were generally good, as only one cohort study was rated as having a high risk of bias and one cross-sectional study was rated as unsatisfactory.

While some may consider including high or unsatisfactory risk of bias studies in the meta-analysis as a potential limitation, the researchers addressed these concerns in both the methods and results sections. The risk of bias appraisal tool was adapted to fit the overall review question, but there is one domain around comparibility which could not be adapted and may have inflated high risk of bias in cohort and cross-sectional studies which did not have a comparison group. For this reason and in line with other meta-analysis reviews, the

researchers included all studies regardless of their risk of bias rating (Lai et al., 2019; Varcin et al., 2022). Whilst this could impact the overall reliability of the findings, the analysis also included several tests to check for outlier studies and publication bias. Another possibility for controlling for high or unsatisfactory risk of bias was to use the overall risk of bias scores in a meta-regression or to use the overall rating categories in a subgroup analysis.

Another potential criticism of this review might be that the high levels of heterogeneity, particularly in the adult study category data, may favour a narrative synthesis rather than a meta-analysis. However, conducting a meta-analysis allowed a direct comparison of prevalence rates and assignment of weights across studies, creating a weighted pooled prevalence that is at least as important as individual prevalence study estimates (Daveney et al., 2019). Researchers also accounted for heterogeneity by applying a random effects model to pool prevalence rates, and outlier analysis was used to identify sources of heterogeneity. Overall, heterogeneity levels were reduced to low and zero for current and lifetime child-adolescent studies, respectively, while remaining high and moderate to high for current and lifetime adult studies. Moreover, exploratory subgroup analysis assisted in identifying the sources of heterogeneity (Appendix 4b, 5b, and 7b). Finally, the search was restricted to studies published in English, potentially excluding relevant studies in other languages. Grey literature was also excluded under the assumption that high-quality studies would be available in peer-reviewed journals. However, this could have inadvertently introduced selection bias. Notably, publication bias was observed in the current child-adolescent PTSD prevalence meta-analysis.

4.4 Clinical implications and future research

Based on the above findings, autistic child-adolescent recorded PTSD prevalence rates are similar to those observed in the general population. However, studies using assessment methods that focussed on PTSD symptoms produced higher prevalence rates. This suggests that future studies should investigate the impact of assessment methods on PTSD diagnosis within autism populations, including the exploration of measures that emphasise externalising

symptoms to determine if they yield different results. Similarly, the current review did not consider complex PTSD within autistic populations who are likely to have experienced a lifetime of traumatic experiences. As such, individuals might have PTSD-related symptoms for long periods rather than having a sudden onset, which may be more typical for neurotypical populations. This is particularly important when considering that autistic individuals may experience many traumatic events that do not occur in neurotypical populations, such as physical restraint when distressed or blocked escape (Stack & Lucyshyn, 2019).

Regarding autistic adult populations, the recorded PTSD prevalence rates are lower than those observed in the general population. These findings are particularly concerning, considering that autistic individuals are more likely to have experienced traumatic events, and evidence suggests higher post-traumatic symptomology in probable autistic populations (Haruvi-Lamdan et al., 2020; Rumball et al., 2021; Stewart et al., 2022). Therefore, future studies should investigate why these figures are lower than those found in other studies and within the child-adolescent study category. One potential recommendation for clinicians is to incorporate multiple sources of information, such as input from family members or close friends, when assessing PTSD in autistic adults. This is important because autistic individuals may face challenges in self-reporting traumatic or emotional difficulties (Ben Shalom et al., 2006; Mazefsky et al., 2011). Exploratory subgroup analysis also revealed that factors such as ethnicity (minoritised backgrounds), gender (females), and the presence of intellectual disability may be associated with reduced PTSD prevalence rates in autistic adult populations. This warrants further investigation, and it might be beneficial for clinicians or services to be mindful of missed PTSD diagnoses when assessing autistic adults with these characteristics.

4.5 Conclusion

One potential conclusion that can be drawn from the current review is that despite relatively low levels of PTSD, levels of trauma are still likely to be high among autistic individuals. However, PTSD diagnostic criteria might result in an underestimation of trauma-related symptomology. This is supported by multiple studies indicating that individuals with high

numbers of autistic traits are more susceptible to experiencing traumatic events and exhibit higher rates of traumatic symptomology that meet the clinical threshold for PTSD (Stewart et al., 2022; Haruvi-Lamdan et al., 2020; Rumball et al., 2021). These findings emphasise the importance of reconsidering the diagnostic criteria for PTSD to identify and address trauma in autistic individuals. By expanding the criteria to account for the unique challenges faced by autistic individuals and considering difficulties in self-reporting, we can ensure that more individuals receive appropriate support and have access to trauma-focused treatments that can benefit their recovery.

References

Alegría, M., Fortuna, L. R., Lin, J. Y., Norris, F. H., Gao, S., Takeuchi, D. T., Jackson, J. S., Shrout, P. E., & Valentine, A. (2013). Prevalence, Risk, and Correlates of Posttraumatic Stress Disorder Across Ethnic and Racial Minority Groups in the United States. *Medical Care*, *51*(12), 1114–1123. https://doi.org/10.1097/mlr.0000000000000007

American Psychiatric Association. (2022a). Neurodevelopmental Disorders. In Diagnostic and Statistical Manual of Mental Disorders (5th ed., text rev.). https://dsm.psychiatryonline.org/doi/10.1176/appi.books.9780890425787.x01_Neurodevelopmental_Disorders

American Psychiatric Association. (2022b). Trauma- and Stressor-Related Disorders. In Diagnostic and Statistical Manual of Mental Disorders (5th ed., text rev.). https://dsm.psychiatryonline.org/doi/10.1176/appi.books.9780890425787.x07_Trauma_and_Stressor_Related_Disorders

Angold, A., & Costello, E. J. (2000). The Child and Adolescent Psychiatric Assessment (CAPA). *Journal of the American Academy of Child & Adolescent Psychiatry*, *39*(1), 39–48. https://doi.org/10.1097/00004583-200001000-00015

Barendregt, J. J., Doi, S. A., Lee, Y. Y., Norman, R. E., & Vos, T. (2013). Meta-analysis of prevalence. J Epidemiol Community Health, 67(11), 974-978.

Baxter, A. J., Brugha, T. S., Erskine, H. E., Scheurer, R. W., Vos, T., & Scott, J. G. (2015). The epidemiology and global burden of autism spectrum disorders. *Psychological Medicine*, *45*(3), 601–613. https://doi.org/10.1017/S003329171400172X

Bell, A., Fairbrother, M., & Jones, K. (2019). Fixed and random effects models: making an informed choice. Quality & quantity, 53, 1051-1074.

Ben Shalom, D., Mostofsky, S. H., Hazlett, R. L., Goldberg, M. C., Landa, R. J., Faran, Y., McLeod, D. R., & Hoehn-Saric, R. (2006). Normal Physiological Emotions but Differences in Expression of Conscious Feelings in Children with High-Functioning Autism. *Journal of Autism and Developmental Disorders*, *36*(3), 395–400. https://doi.org/10.1007/s10803-006-0077-2

Benjet, C., Bromet, E., Karam, E. G., Kessler, R. C., McLaughlin, K. A., Ruscio, A. M., Shahly, V., Stein, D. J., Petukhova, M., Hill, E., Alonso, J., Atwoli, L., Bunting, B., Bruffaerts, R., Caldas-de-Almeida, J. M., de Girolamo, G., Florescu, S., Gureje, O., Huang, Y., & Lepine, J. P. (2016). The epidemiology of traumatic event exposure worldwide: results from the World Mental Health Survey Consortium. *Psychological Medicine*, *46*(02), 327–343. https://doi.org/10.1017/s0033291715001981

Bitsika, V., & Sharpley, C. F. (2014). Variation in the Profile of Anxiety Disorders in Boys with an ASD According to Method and Source of Assessment. *Journal of Autism and Developmental Disorders*, *45*(6), 1825–1835. https://doi.org/10.1007/s10803-014-2343-z

Bivarchi, F. A., Kehyayan, V., & Al-Kohji, S. M. (2021). Barriers to the early detection and intervention of children with autism spectrum disorders: A literature. Journal of Nursing Education and Practice, 11(11).

Borenstein, M., Higgins, J. P., Hedges, L. V., & Rothstein, H. R. (2017). Basics of meta-analysis: I2 is not an absolute measure of heterogeneity. Research synthesis methods, 8(1), 5-18.

Brady, K. T., Killeen, T. K., Brewerton, T., & Lucerini, S. (2000). Comorbidity of psychiatric disorders and posttraumatic stress disorder. Journal of clinical psychiatry, 61(7), 22-

32

Bramer, W. M., Rethlefsen, M. L., Kleijnen, J., & Franco, O. H. (2017). Optimal Database Combinations for Literature Searches in Systematic reviews: a Prospective Exploratory Study. *Systematic Reviews*, *6*(1), 1–12. https://doi.org/10.1186/s13643-017-0644-y

Brenner, J., Pan, Z., Mazefsky, C., Smith, K. A., & Gabriels, R. (2017). Behavioral Symptoms of Reported Abuse in Children and Adolescents with Autism Spectrum Disorder in Inpatient Settings. *Journal of Autism and Developmental Disorders*, *48*(11), 3727–3735. https://doi.org/10.1007/s10803-017-3183-4

Breslau, N., Lucia, V. C., & Alvarado, G. F. (2006). Intelligence and Other Predisposing Factors in Exposure to Trauma and Posttraumatic Stress Disorder. *Archives of General Psychiatry*, *63*(11), 1238. https://doi.org/10.1001/archpsyc.63.11.1238

Brewin, C. R., Lanius, R. A., Novac, A., Schnyder, U., & Galea, S. (2009). Reformulating PTSD forDSM-V: Life after Criterion A. *Journal of Traumatic Stress*, *22*(5), 366–373. https://doi.org/10.1002/jts.20443

Brewin, C. R., Rumball, F., & Happé, F. (2019). Neglected causes of post-traumatic stress disorder. *BMJ*, l2372. https://doi.org/10.1136/bmj.l2372

Broquere, M., Soussana, M., Michelon, C., Rattaz, C., Brisot, J., & Baghdadli, A. (2016). Impact of anxiety disorders on quality of life of adolescents with autism spectrum disorder without intellectual disability. L'encephale, 42(6), 499-505.

Bryson, S. A., Corrigan, S. K., Mcdonald, T. P., & Holmes, C. (2008). Characteristics of children with autism spectrum disorders who received services through community mental health centers. *Autism*, *12*(1), 65–82. https://doi.org/10.1177/1362361307085214

Cook, E. H., Kieffer, J. E., Charak, D. A., & Leventhal, B. L. (1993). Autistic Disorder and Post-Traumatic Stress Disorder. *Journal of the American Academy of Child & Adolescent Psychiatry*, *32*(6), 1292–1294. https://doi.org/10.1097/00004583-199311000-00025

Daveney, J., Hassiotis, A., Katona, C., Matcham, F., & Sen, P. (2019). Ascertainment and Prevalence of Post-Traumatic Stress Disorder (PTSD) in People with Intellectual Disabilities. *Journal of Mental Health Research in Intellectual Disabilities*, *12*(3-4), pp. 211–233. https://doi.org/10.1080/19315864.2019.1637979

de Vries, G.-J., & Olff, M. (2009). The lifetime prevalence of traumatic events and posttraumatic stress disorder in the Netherlands. *Journal of Traumatic Stress*, *22*(4), 259–267. https://doi.org/10.1002/jts.20429

Dell'Osso, L., Dalle Luche, R., & Carmassi, C. (2015). A new perspective in post-traumatic stress disorder: which role for unrecognized autism spectrum. International Journal of Emergency Mental Health and Human Resilience, 17(2), 436-438.

Dube, S. R., Miller, J. W., Brown, D. W., Giles, W. H., Felitti, V. J., Dong, M., & Anda, R. F. (2006). Adverse childhood experiences and the association with ever using alcohol and initiating alcohol use during adolescence. Journal of Adolescent Health, 38(4), 444-e1.

Dückers, M. L. A., Alisic, E., & Brewin, C. R. (2016). A vulnerability paradox in the cross-national prevalence of post-traumatic stress disorder. *British Journal of Psychiatry*, *209*(4), 300–305. https://doi.org/10.1192/bjp.bp.115.176628

Egger, M., Smith, G. D., Schneider, M., & Minder, C. (1997). Bias in meta-analysis detected by a simple, graphical test. *BMJ*, *315*(7109), 629–634. https://doi.org/10.1136/bmj.315.7109.629

Farrah, K., Young, K., Tunis, M. C., & Zhao, L. (2019). Risk of Bias Tools in Systematic Reviews of Health interventions: an Analysis of PROSPERO-registered Protocols. *Systematic Reviews*, *8*(1), 1–9. https://doi.org/10.1186/s13643-019-1172-8

First, M. B., & Gibbon, M. (2004). The structured clinical interview for DSM-IV axis I disorders (SCID-I) and the structured clinical interview for DSM-IV axis II disorders (SCID-II). In M. J. Hilsenroth & D. L. Segal (Eds.), Comprehensive handbook of psychological assessment, Vol. 2. Personality assessment (pp. 134–143). John Wiley & Sons, Inc..

Geurts, H. M., Charlton, R. A., & Bishop, L. (2021). Ageing when being autistic. In M. Putnam & C. Bigby (Eds.), Handbook on Ageing with Disability (pp 148-157). Routledge Abington.

Gillberg, C., Gillberg, C., Råstam, M., & Wentz, E. (2001). The Asperger Syndrome (and High-Functioning Autism) Diagnostic Interview (ASDI): A Preliminary Study of a New Structured Clinical Interview. *Autism*, *5*(1), 57–66. https://doi.org/10.1177/1362361301005001006

Gillberg, I. C., Helles, A., Billstedt, E., & Gillberg, C. (2015). Boys with Asperger Syndrome Grow Up: Psychiatric and Neurodevelopmental Disorders 20 Years After Initial Diagnosis. *Journal of Autism and Developmental Disorders*, *46*(1), 74–82. https://doi.org/10.1007/s10803-015-2544-0

Goodman, R., Ford, T., Richards, H., Gatward, R., & Meltzer, H. (2000). The Development and Well-Being Assessment: Description and Initial Validation of an Integrated Assessment of Child and Adolescent Psychopathology. *Journal of Child Psychology and Psychiatry*, *41*(5), 645–655. https://doi.org/10.1111/j.1469-7610.2000.tb02345.x

Happé, F., & Frith, U. (2020). Annual Research Review: Looking back to look forward – changes in the concept of autism and implications for future research. *Journal of Child Psychology and Psychiatry*, *61*(3), 218–232. https://doi.org/10.1111/jcpp.13176

Haruvi-Lamdan, N., Horesh, D., & Golan, O. (2018). PTSD and autism spectrum disorder: Co-morbidity, gaps in research, and potential shared mechanisms. *Psychological Trauma: Theory, Research, Practice, and Policy*, *10*(3), 290–299. https://doi.org/10.1037/tra0000298

Haruvi-Lamdan, N., Horesh, D., Zohar, S., Kraus, M., & Golan, O. (2020). Autism Spectrum Disorder and Post-Traumatic Stress Disorder: An unexplored co-occurrence of conditions. *Autism*, *24*(4), 884–898. https://doi.org/10.1177/1362361320912143

Herzog, R., Álvarez-Pasquin, M., Díaz, C., Del Barrio, J. L., Estrada, J. M., & Gil, Á. (2013). Are healthcare workers' intentions to vaccinate related to their knowledge, beliefs and attitudes? A systematic review. BMC public health, 13(1), 1-17.

Hien, D., Matzner, F. J., First, M. B., Spitzer, R. L., Williams, J., & Gibbon, M. (1994). Structured Clinical Interview for DSM-IV Childhood Diagnoses (KID-SCID). New York, Biometrics Research Presentation. Smith, DC, Huber, DL, & Hall, JA (2005). Psychometric evaluation of the structured clinical interview for DSMIV childhood diagnoses (KID-SCID). Journal of Human Behavior in the Social Environment, 11, 3-4.

Higgins, J. P. T., Altman, D. G., Gotzsche, P. C., Juni, P., Moher, D., Oxman, A. D., Savovic, J., Schulz, K. F., Weeks, L., & Sterne, J. A. C. (2011). The Cochrane Collaboration's tool for assessing risk of bias in randomised trials. *BMJ*, *343*(343). https://doi.org/10.1136/bmj.d5928

Hoch, J. D., & Youssef, A. M. (2019). Predictors of Trauma Exposure and Trauma Diagnoses for Children with Autism and Developmental Disorders Served in a Community Mental Health Clinic. *Journal of Autism and Developmental Disorders*, *50*(2), 634–649. https://doi.org/10.1007/s10803-019-04331-3

Hofvander, B., Delorme, R., Chaste, P., Nydén, A., Wentz, E., Ståhlberg, O., Herbrecht, E., Stopin, A., Anckarsäter, H., Gillberg, C., Råstam, M., & Leboyer, M. (2009). Psychiatric and psychosocial problems in adults with normal-intelligence autism spectrum disorders. *BMC Psychiatry*, *9*(1), 1–9. https://doi.org/10.1186/1471-244x-9-35

Hollocks, M. J., Pickles, A., Howlin, P., & Simonoff, E. (2016). Dual Cognitive and Biological Correlates of Anxiety in Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, *46*(10), 3295–3307. https://doi.org/10.1007/s10803-016-2878-2

Holly, A., & Wittchen, H. U. (1998). Patterns of use and their relationship to DSM-IV abuse and dependence of alcohol among adolescents and young adults. European addiction research, 4(1-2), 50-57.

Hoover, D. W. (2015). The Effects of Psychological Trauma on Children with Autism Spectrum Disorders: a Research Review. *Review Journal of Autism and*

Developmental Disorders, *2*(3), 287–299. https://doi.org/10.1007/s40489-015-0052-y

Hossain, M. M., Khan, N., Sultana, A., Ma, P., McKyer, E. Lisako J., Ahmed, H. U., & Purohit, N. (2020). Prevalence of comorbid psychiatric disorders among people with autism spectrum disorder: An umbrella review of systematic reviews and meta-analyses. *Psychiatry Research*, *287*, 112922. https://doi.org/10.1016/j.psychres.2020.112922

Howlin, P., & Clements, J. (1995). Is it possible to assess the impact of abuse on children with pervasive developmental disorders? *Journal of Autism and Developmental Disorders*, *25*(4), 337–354. https://doi.org/10.1007/bf02179372

Huang, Y., Arnold, S. R., Foley, K.-R., & Trollor, J. N. (2020). Diagnosis of autism in adulthood: A scoping review. *Autism*, *24*(6), 1311–1327. https://doi.org/10.1177/1362361320903128

Joshi, G., Faraone, S. V., Wozniak, J., Petty, C., Fried, R., Galdo, M., Furtak, S. L., McDermott, K., Epstien, C., Walker, R., Caron, A., Feinberg, L., & Biederman, J. (2014). Examining the Clinical Correlates of Autism Spectrum Disorder in Youth by Ascertainment Source. *Journal of Autism and Developmental Disorders*, *44*(9), 2117–2126. https://doi.org/10.1007/s10803-014-2063-4

Joshi, G., Wozniak, J., Petty, C., Martelon, M. K., Fried, R., Bolfek, A., Kotte, A., Stevens, J., Furtak, S. L., Bourgeois, M., Caruso, J., Caron, A., & Biederman, J. (2013). Psychiatric comorbidity and functioning in a clinically referred population of adults with autism spectrum disorders: a comparative study. *Journal of Autism and Developmental Disorders*, *43*(6), 1314–1325. https://doi.org/10.1007/s10803-012-1679-5

Kaufman, J., Birmaher, B., Brent, D., Rao, U., Flynn, C., Moreci, P., Williamson, D., & Ryan, N. (1997). Schedule for Affective Disorders and Schizophrenia for School-Age Children-Present and Lifetime Version (K-SADS-PL): Initial Reliability and Validity Data. *Journal of the American Academy of Child & Adolescent Psychiatry*, *36*(7), 980–988. https://doi.org/10.1097/00004583-199707000-00021

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

Kerns, C. M., Newschaffer, C. J., & Berkowitz, S. J. (2015). Traumatic Childhood Events and Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, *45*(11), 3475–3486. https://doi.org/10.1007/s10803-015-2392-y

Kildahl, A. N., Bakken, T. L., Iversen, T. E., & Helverschou, S. B. (2019). Identification of Post-Traumatic Stress Disorder in Individuals with Autism Spectrum Disorder and Intellectual Disability: A Systematic Review. *Journal of Mental Health Research in Intellectual Disabilities*, *12*(1-2), 1–25. https://doi.org/10.1080/19315864.2019.1595233

King, R., & Desaulnier, C. L. (2011). Commentary: Complex Post-Traumatic Stress Disorder. Implications for Individuals with Autism Spectrum Disorders--Part II. Journal on Developmental Disabilities, 17(1), 47-59

Koenen, K. C., Ratanatharathorn, A., Ng, L., McLaughlin, K. A., Bromet, E. J., Stein, D. J., Karam, E. G., Meron Ruscio, A., Benjet, C., Scott, K., Atwoli, L., Petukhova, M., Lim, C. C. W., Aguilar-Gaxiola, S., Al-Hamzawi, A., Alonso, J., Bunting, B., Ciutan, M., de Girolamo, G., & Degenhardt, L. (2017). Posttraumatic stress disorder in the World Mental Health Surveys. *Psychological Medicine*, *47*(13), 2260–2274. https://doi.org/10.1017/s0033291717000708

Kreiser, N. L., & White, S. W. (2013). ASD in Females: Are We Overstating the Gender Difference in Diagnosis? *Clinical Child and Family Psychology Review*, *17*(1), 67–84. https://doi.org/10.1007/s10567-013-0148-9

Kusaka, H., Dai Miyawaki, Nakai, Y., Okamoto, H., Eri Futoo, Goto, A., Okada, Y., & Inoue, K. (2014). Psychiatric comorbidity in children with high-functioning pervasive developmental disorder. *Osaka City Medical Journal*, *60*(1), 1–10.

Landis, J.R.; Koch, G.G. (1977). The measurement of observer agreement for categorical data. Biometrics. 33 (1): 159-174. https://doi.org/10.2307%2F2529310

Lai, M.-C., Kassee, C., Besney, R., Bonato, S., Hull, L., Mandy, W., Szatmari, P., & Ameis, S. H. (2019). Prevalence of co-occurring mental health diagnoses in the autism population: a systematic review and meta-analysis. *The Lancet Psychiatry*, *6*(10), 819–829. https://doi.org/10.1016/s2215-0366(19)30289-5

Lecavalier, L. (2006). Behavioral and Emotional Problems in Young People with Pervasive Developmental Disorders: Relative Prevalence, Effects of Subject Characteristics, and Empirical Classification. *Journal of Autism and Developmental Disorders*, *36*(8), 1101–1114. https://doi.org/10.1007/s10803-006-0147-5

Lever, A. G., & Geurts, H. M. (2016). Psychiatric Co-occurring Symptoms and Disorders in Young, Middle-Aged, and Older Adults with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, *46*(6), 1916–1930. https://doi.org/10.1007/s10803-016-2722-8

Lord, C., Risi, S., Lambrecht, L., Cook, Jr., E. H., Leventhal, B. L., DiLavore, P. C., Pickles, A., & Rutter, M. (2000). The Autism Diagnostic Observation Schedule—Generic: A Standard Measure of Social and Communication Deficits Associated with the Spectrum of Autism. *Journal of Autism and Developmental Disorders*, *30*(3), 205–223. https://doi.org/10.1023/a:1005592401947

Lugnegård, T., Hallerbäck, M. U., & Gillberg, C. (2011). Psychiatric comorbidity in young adults with a clinical diagnosis of Asperger syndrome. *Research in Developmental Disabilities*, *32*(5), 1910–1917. https://doi.org/10.1016/j.ridd.2011.03.025

Lugo-Marín, J., Magán-Maganto, M., Rivero-Santana, A., Cuellar-Pompa, L., Alviani, M., Jenaro-Rio, C., Díez, E., & Canal-Bedia, R. (2019). Prevalence of psychiatric disorders in adults with autism spectrum disorder: A systematic review and meta-analysis. *Research in Autism Spectrum Disorders*, *59*, 22–33. https://doi.org/10.1016/j.rasd.2018.12.004

Maenner, M. J. (2020). Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2016. *MMWR. Surveillance Summaries*, *69*(4), 1–12.

https://doi.org/10.15585/mmwr.ss6904a1

Mandell, D. S., Walrath, C. M., Manteuffel, B., Sgro, G., & Pinto-Martin, J. A. (2005). The prevalence and correlates of abuse among children with autism served in comprehensive community-based mental health settings. *Child Abuse & Neglect*, *29*(12), 1359–1372. https://doi.org/10.1016/j.chiabu.2005.06.006

Mansell, S., Sobsey, D., & Moskal, R. (1998). Clinical Findings Among Sexually Abused Children With and Without Developmental Disabilities. *Mental Retardation*, *36*(1), 12–22. https://doi.org/10.1352/0047-6765(1998)036%3C0012:cfasac%3E2.0.co;2

Mansour, H., Mueller, C., Davis, K. A., Burton, A., Shetty, H., Hotopf, M., ... & Sommerlad, A. (2020). Severe mental illness diagnosis in English general hospitals 2006-2017: a registry linkage study. PLoS medicine, 17(9), e1003306.

Mansour, R., Dovi, A. T., Lane, D. M., Loveland, K. A., & Pearson, D. A. (2017). ADHD severity as it relates to comorbid psychiatric symptomatology in children with Autism Spectrum Disorders (ASD). *Research in Developmental Disabilities*, *60*, 52–64. https://doi.org/10.1016/j.ridd.2016.11.009

Mazefsky, C. A., Kao, J., & Oswald, D. P. (2011). Preliminary evidence suggesting caution in the use of psychiatric self-report measures with adolescents with high-functioning autism spectrum disorders. *Research in Autism Spectrum Disorders*, *5*(1), 164–174. https://doi.org/10.1016/j.rasd.2010.03.006

McLaughlin, K. A., Koenen, K. C., Hill, E. D., Petukhova, M., Sampson, N. A., Zaslavsky, A. M., & Kessler, R. C. (2013). Trauma Exposure and Posttraumatic Stress Disorder in a National Sample of Adolescents. *Journal of the American Academy of Child & Adolescent Psychiatry*, *52*(8), 815-830.e14. https://doi.org/10.1016/j.jaac.2013.05.011

McNally, P., Taggart, L., & Shevlin, M. (2021). Trauma experiences of people with an intellectual disability and their implications: A scoping review. *Journal of Applied Research in Intellectual Disabilities*, *34*(4), 927–949. https://doi.org/10.1111/jar.12872

Mehtar, M., & Mukaddes, N. M. (2011). Posttraumatic Stress Disorder in individuals with

diagnosis of Autistic Spectrum Disorders. *Research in Autism Spectrum Disorders*, *5*(1), 539–546. https://doi.org/10.1016/j.rasd.2010.06.020

Mevissen, L., & de Jongh, A. (2010). PTSD and its treatment in people with intellectual disabilities. *Clinical Psychology Review*, *30*(3), 308–316. https://doi.org/10.1016/j.cpr.2009.12.005

Moher, D., Shamseer, L., Clarke, M., Ghersi, D., Liberati, A., Petticrew, M., Shekelle, P., & Stewart, L. A. (2015). Preferred Reporting Items for Systematic Review and meta-analysis Protocols (PRISMA-P) 2015 Statement. *Systematic Reviews*, *4*(1), 1–9. https://doi.org/10.1186/2046-4053-4-1

Morgan, M. A., Kelber, M. S., O'Gallagher, K., Liu, X., Evatt, D. P., & Belsher, B. E. (2019). Discrepancies in diagnostic records of military service members with self-reported PTSD: healthcare use and longitudinal symptom outcomes. General hospital psychiatry, 58, 33-38.

Muskens, J. B., Velders, F. P., & Staal, W. G. (2017). Medical comorbidities in children and adolescents with autism spectrum disorders and attention deficit hyperactivity disorders: a systematic review. *European Child & Adolescent Psychiatry*, *26*(9), 1093–1103. https://doi.org/10.1007/s00787-017-1020-0

Nimmo-Smith, V., Heuvelman, H., Dalman, C., Lundberg, M., Idring, S., Carpenter, P., Magnusson, C., & Rai, D. (2019). Anxiety Disorders in Adults with Autism Spectrum Disorder: A Population-Based Study. *Journal of Autism and Developmental Disorders*, *50*(1), 308–318. https://doi.org/10.1007/s10803-019-04234-3

Orinstein, A., Tyson, K. E., Suh, J., Troyb, E., Helt, M., Rosenthal, M., Barton, M. L., Eigsti, I.-M., Kelley, E., Naigles, L., Schultz, R. T., Stevens, M. C., & Fein, D. A. (2015). Psychiatric Symptoms in Youth with a History of Autism and Optimal Outcome. *Journal of Autism and Developmental Disorders*, *45*(11), 3703–3714. https://doi.org/10.1007/s10803-015-2520-8

Ouzzani, M., Hammady, H., Fedorowicz, Z., & Elmagarmid, A. (2016). Rayyan—a web and mobile app for systematic reviews. Systematic reviews, 5, 1-10.

Perkonigg, A., Kessler, R. C., Storz, S., & Wittchen, H-U. (2000). Traumatic events and post-traumatic stress disorder in the community: prevalence,risk factors and comorbidity. *Acta Psychiatrica Scandinavica*, *101*(1), 46–59. https://doi.org/10.1034/j.1600-0447.2000.101001046.x

Peterson, J. L., Earl, R. K., Fox, E. A., Ma, R., Haidar, G., Pepper, M., Berliner, L., Wallace, A. S., & Bernier, R. A. (2019). Trauma and Autism Spectrum Disorder: Review, Proposed Treatment Adaptations and Future Directions. *Journal of Child & Adolescent Trauma*, *12*(4), 529–547. https://doi.org/10.1007/s40653-019-00253-5

Plesa Skwerer, D., Joseph, R. M., Eggleston, B., Meyer, S. R., & Tager-Flusberg, H. (2019). Prevalence and Correlates of Psychiatric Symptoms in Minimally Verbal Children and Adolescents With ASD. *Frontiers in Psychiatry*, *10*, 43. https://doi.org/10.3389/fpsyt.2019.00043

Reich, W. (2000). Diagnostic interview for children and adolescents (DICA). Journal of the American Academy of Child & Adolescent Psychiatry, 39(1), 59-66.

Reinvall, O., Moisio, A.-L., Lahti-Nuuttila, P., Voutilainen, A., Laasonen, M., & Kujala, T. (2016). Psychiatric symptoms in children and adolescents with higher functioning autism spectrum disorders on the Development and Well-Being Assessment. *Research in Autism Spectrum Disorders*, *25*, 47–57. https://doi.org/10.1016/j.rasd.2016.01.009

Reiss, S., Levitan, G. W., & Szyszko, J. (1982). Emotional disturbance and mental retardation: Diagnostic overshadowing. American Journal of Mental Deficiency, 86(6), 567–574.

Rittmannsberger, D., Yanagida, T., Weber, G., & Lueger-Schuster, B. (2020). The association between challenging behaviour and symptoms of post-traumatic stress disorder in people with intellectual disabilities: a Bayesian mediation analysis approach. *Journal of Intellectual Disability Research*, *64*(7), 538–550. https://doi.org/10.1111/jir.12733

Robison, J. E. (2019). Talking about autism—thoughts for researchers. *Autism Research*,

12(7), 1004–1006. https://doi.org/10.1002/aur.2119

Roy, M., Prox-Vagedes, V., Ohlmeier, M. D., & Wolfgang Dillo. (2015). Beyond childhood: psychiatric comorbidities and social background of adults with Asperger syndrome. *Psychiatria Danubina*, *27*(1), 50–59.

Rumball, F. (2019). A Systematic Review of the Assessment and Treatment of Posttraumatic Stress Disorder in Individuals with Autism Spectrum Disorders. *Review Journal of Autism and Developmental Disorders*, *6*(3), 294–324. https://doi.org/10.1007/s40489-018-0133-9

Rumball, F., Brook, L., Happé, F., & Karl, A. (2021). Heightened risk of posttraumatic stress disorder in adults with autism spectrum disorder: The role of cumulative trauma and memory deficits. *Research in Developmental Disabilities*, *110*, 103848. https://doi.org/10.1016/j.ridd.2020.103848

Russell, A. J., Murphy, C. M., Wilson, E., Gillan, N., Brown, C., Robertson, D. M., Craig, M. C., Deeley, Q., Zinkstok, J., Johnston, K., McAlonan, G. M., Spain, D., & Murphy, D. G. (2015). The mental health of individuals referred for assessment of autism spectrum disorder in adulthood: A clinic report. *Autism*, *20*(5), 623–627. https://doi.org/10.1177/1362361315604271

Rydén, E., & Bejerot, S. (2008). Autism spectrum disorder in an adult psychiatric population : A naturalistic cross sectional controlled study. *Clinical Neuropsychiatry*, *5*(1), 13–21. http://urn.kb.se/resolve?urn=urn:nbn:se:oru:diva-50194

Salazar, F., Baird, G., Chandler, S., Tseng, E., O'sullivan, T., Howlin, P., Pickles, A., & Simonoff, E. (2015). Co-occurring Psychiatric Disorders in Preschool and Elementary School-Aged Children with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, *45*(8), 2283–2294. https://doi.org/10.1007/s10803-015-2361-5

Schendel, D. E., Overgaard, M., Christensen, J., Hjort, L., Jørgensen, M., Vestergaard, M., & Parner, E. T. (2016). Association of Psychiatric and Neurologic Comorbidity With Mortality Among Persons With Autism Spectrum Disorder in a Danish Population.

JAMA Pediatrics, *170*(3), 243–250. https://doi.org/10.1001/jamapediatrics.2015.3935

Schopler, E., Reichler, R. J., & Renner, B. R. (2010). The childhood autism rating scale (CARS). Los Angeles, CA: Western Psychological Services.

Scott, H. M., & Havercamp, S. M. (2018). Comparisons of self and proxy report on health-related factors in people with intellectual disability. Journal of Applied Research in Intellectual Disabilities, 31(5), 927-936.

Sedgewick, F., Leppanen, J., & Tchanturia, K. (2020). Gender differences in mental health prevalence in autism. *Advances in Autism*, *7*(3), 208–224. https://doi.org/10.1108/aia-01-2020-0007

Shaffer, D., Fisher, P., Lucas, C. P., Dulcan, M. K., & Schwab-Stone, M. E. (2000). NIMH Diagnostic Interview Schedule for Children Version IV (NIMH DISC-IV): Description, Differences From Previous Versions, and Reliability of Some Common Diagnoses. *Journal of the American Academy of Child & Adolescent Psychiatry*, *39*(1), 28–38. https://doi.org/10.1097/00004583-200001000-00014

Shah, A. D., Quinn, N. J., Chaudhry, A., Sullivan, R., Costello, J., O'Riordan, D., ... & Williams, J. G. (2019). Recording problems and diagnoses in clinical care: developing guidance for healthcare professionals and system designers. BMJ health & care informatics, 26(1).

Shalev, A. Y., Gevonden, M., Ratanatharathorn, A., Laska, E., van der Mei, W. F., Qi, W., Lowe, S., Lai, B. S., Bryant, R. A., Delahanty, D., Matsuoka, Y. J., Olff, M., Schnyder, U., Seedat, S., deRoon-Cassini, T. A., Kessler, R. C., & Koenen, K. C. (2019). Estimating the risk of PTSD in recent trauma survivors: results of the International Consortium to Predict PTSD (ICPP). *World Psychiatry*, *18*(1), 77–87. https://doi.org/10.1002/wps.20608

Sheehan, D. V., Lecrubier, Y., Sheehan, K. H., Amorim, P., Janavs, J., Weiller, E., ... & Dunbar, G. C. (1998). The Mini-International Neuropsychiatric Interview (MINI): the development and validation of a structured diagnostic psychiatric interview for DSM-IV and ICD-10. Journal of clinical psychiatry, 59(20), 22-33.

Simonoff, E., Jones, C. R. G., Baird, G., Pickles, A., Happé, F., & Charman, T. (2012). The persistence and stability of psychiatric problems in adolescents with autism spectrum disorders. *Journal of Child Psychology and Psychiatry*, *54*(2), 186–194. https://doi.org/10.1111/j.1469-7610.2012.02606.x

Song, F., Sheldon, T. A., Sutton, A. J., Abrams, K. R., & Jones, D. R. (2001). Methods for Exploring Heterogeneity in Meta-Analysis. *Evaluation & the Health Professions*, *24*(2), 126–151. https://doi.org/10.1177/016327870102400203

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

Stewart, G. R., Corbett, A., Ballard, C., Creese, B., Aarsland, D., Hampshire, A., ... & Happé, F. (2022). Traumatic life experiences and post-traumatic stress symptoms in middle-aged and older adults with and without autistic traits. International journal of geriatric psychiatry, 37(2).

Storch, E. A., Sulkowski, M. L., Nadeau, J., Lewin, A. B., Arnold, E. B., Mutch, P. J., ... & Murphy, T. K. (2013). The phenomenology and clinical correlates of suicidal thoughts and behaviors in youth with autism spectrum disorders. Journal of autism and developmental disorders, 43, 2450-2459.

Strunz, S., Dziobek, I., & Roepke, S. (2013). Comorbid psychiatric disorders and differential diagnosis of patients with autism spectrum disorder without intellectual disability. Psychotherapie, Psychosomatik, Medizinische Psychologie, 64(6), 206-213

Taylor, J. L., & Gotham, K. O. (2016). Cumulative life events, traumatic experiences, and psychiatric symptomatology in transition-aged youth with autism spectrum disorder. *Journal of Neurodevelopmental Disorders*, *8*(1), 1–11. https://doi.org/10.1186/s11689-016-9160-y

Tromans, S., Chester, V., Gemegah, E., Roberts, K., Morgan, Z., Yao, G. L., & Brugha, T. (2020). Autism identification across ethnic groups: a narrative review. *Advances in*

Autism, *7*(3), 241–255. https://doi.org/10.1108/aia-03-2020-0017

Trundle, G., Jones, K. A., Ropar, D., & Egan, V. (2022). Prevalence of Victimisation in Autistic Individuals: A Systematic Review and Meta-Analysis. *Trauma, Violence & Abuse*, *0*(0), 1–15. https://doi.org/10.1177/15248380221093689

Underwood, J. F. G., Kendall, K. M., Berrett, J., Lewis, C., Anney, R., van den Bree, M. B. M., & Hall, J. (2019). Autism spectrum disorder diagnosis in adults: phenotype and genotype findings from a clinically derived cohort. *British Journal of Psychiatry*, *215*(5), 647–653. https://doi.org/10.1192/bjp.2019.30

Ung, D., Selles, R., Small, B. J., & Storch, E. A. (2014). A Systematic Review and Meta-Analysis of Cognitive-Behavioral Therapy for Anxiety in Youth with High-Functioning Autism Spectrum Disorders. *Child Psychiatry & Human Development*, *46*(4), 533–547. https://doi.org/10.1007/s10578-014-0494-y

Valenti, M., Ciprietti, T., Egidio, C. D., Gabrielli, M., Masedu, F., Tomassini, A. R., & Sorge, G. (2011). Adaptive Response of Children and Adolescents with Autism to the 2009 Earthquake in L'Aquila, Italy. *Journal of Autism and Developmental Disorders*, *42*(6), 954–960. https://doi.org/10.1007/s10803-011-1323-9

van Steensel, F. J. A., Bögels, S. M., & de Bruin, E. I. (2012). Psychiatric Comorbidity in Children with Autism Spectrum Disorders: A Comparison with Children with ADHD. *Journal of Child and Family Studies*, *22*(3), 368–376. https://doi.org/10.1007/s10826-012-9587-z

Vannucchi, G., Masi, G., Toni, C., Dell'Osso, L., Marazziti, D., & Perugi, G. (2014). Clinical features, developmental course, and psychiatric comorbidity of adult autism spectrum disorders. CNS spectrums, 19(2), 157-164.

Verheij, C., Louwerse, A., van der Ende, J., Eussen, M. L. J. M., Van Gool, A. R., Verheij, F., Verhulst, F. C., & Greaves-Lord, K. (2015). The Stability of Comorbid Psychiatric Disorders: A 7 Year Follow Up of Children with Pervasive Developmental Disorder-Not Otherwise Specified. *Journal of Autism and Developmental Disorders*, *45*(12), 3939–3948. https://doi.org/10.1007/s10803-015-2592-5

Viechtbauer, W., & Cheung, M. W.-L. . (2010). Outlier and influence diagnostics for meta-analysis. *Research Synthesis Methods*, *1*(2), 112–125. https://doi.org/10.1002/jrsm.11

Weathers, F. W., & Keane, T. M. (2007). The Criterion A problem revisited: controversies and challenges in defining and measuring psychological trauma. *Journal of Traumatic Stress*, *20*(2), 107–121. https://doi.org/10.1002/jts.20210

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

Wood, J. J., & Gadow, K. D. (2010). Exploring the Nature and Function of Anxiety in Youth with Autism Spectrum Disorders. *Clinical Psychology: Science and Practice*, *17*(4), 281–292. https://doi.org/10.1111/j.1468-2850.2010.01220.x

World Health Organization. (2022). ICD-11: International classification of diseases (11th revision). https://icd.who.int/

Zeidan, J., Fombonne, E., Scorah, J., Ibrahim, A., Durkin, M. S., Saxena, S., Yusuf, A., Shih, A., & Elsabbagh, M. (2022). Global prevalence of autism: A systematic review update. *Autism Research*, *15*(5), 778–790. https://doi.org/10.1002/aur.2696

Part 2: Empirical Paper

‘It’s designed for someone who is not me’: Reflexive thematic analysis of the healthcare experiences of autistic older adults living in the UK

Abstract

Background: There is evidence to suggest that autistic individuals are more likely to experience physical and mental health difficulties throughout their lives, leading to an increased risk of mortality due to health inequalities (Hand et al., 2020; Rydzewska et al., 2019; Bishop-Fitzpatrick & Kind, 2017; Hirvikoski et al., 2016). While studies have explored the healthcare experiences of younger and middle-aged autistic adults, there is a lack of research on the experiences of autistic older adults aged 65 years or over (Mason et al., 2019; Walsh et al., 2020; Sonido et al., 2020).

Methodology: To address this gap, in-depth semi-structured interviews were conducted with 19 autistic older adults aged 65 years or over and one carer for an autistic older adult aged 68 years with a moderate co-occurring intellectual disability. Participants were interviewed about their experiences of accessing healthcare services in the UK.

Analysis: Reflexive thematic analysis helped co-construct four themes that include the impact of lived experiences on healthcare access challenges, the influence of system and service-level changes, the intersectionality between ageing and autism, and vital policy and practice recommendations.

Interpretation: Autistic older adults encounter distinct healthcare challenges, which have been exacerbated by the pandemic and economic uncertainties. Current services often neglect their lifelong struggles with autism-related issues. Participants expressed concerns about age-related decline and reduced social support. To address these challenges, a comprehensive approach is needed that encompasses policy changes, healthcare adjustments, and improved staff training. Implementing these recommendations and further research is vital to improving the healthcare experiences of neurodivergent and ageing populations.

1. Introduction

Autism is a neurodevelopmental condition characterised by social interaction and communication differences coupled with restricted, repetitive, or stereotypical behaviour patterns that can include sensory sensitivity (American Psychological Association, 2022). Although there are ongoing debates on how best to describe autism, the current study will use identity-first language, as preferred by autistic individuals in lived experience research (Kenny et al., 2016; Robison, 2019). In the United Kingdom (UK), at least 1.1% of the population meets the diagnostic criteria for autism, and 15-29% of those individuals may also have a co-occurring intellectual disability (Brugha et al., 2011; Kinnear et al., 2020).

Although characteristics associated with autism are present from early childhood, they may not be recognised until later in life when social demands exceed the capacity to mask difficulties (Howlin et al., 2004; Cederlund et al., 2008; Happé & Frith, 2020; Geurt et al., 2021). In the last two decades, there has been a significant increase in the number of adults diagnosed with autism, with rates rising from one to 20 per 100,000 individuals diagnosed annually (Brugha et al., 2011; Russell et al., 2022). This increase has been attributed to broadening autism diagnostic criteria and improved understanding of heterogeneous presentations (Rutter, 2005).

1.1 Autism diagnosis in adulthood

As our understanding of autism improves, more adults in middle and later life are being diagnosed with many self-identify as autistic (Russell et al., 2022). However, there is still a significant issue of underdiagnosis, particularly among autistic adults without a co-occurring intellectual disability (ID). According to a report from the Royal College of Psychiatrists, most autistic adults in the UK remain undiagnosed (Royal College of Psychiatrists, 2020). This group of individuals who did not receive a diagnosis during childhood are often referred to as the ‘lost generation’. One suggestion for why their diagnosis may have been missed is because they might have more subtle autistic traits or fewer support needs (Lai & Baron-

Cohen, 2015). However, recent research shows that those diagnosed in adulthood still face significant functional, social, and interpersonal challenges (Atherton et al., 2021). Despite these challenges, there are substantial age-related disparities in access to diagnostic services, with autistic older adults in England being less likely to receive an autism diagnosis than their younger or middle-aged counterparts (O'Nions et al., 2023).

1.2 Post-diagnostic support

Even after an autism diagnosis is obtained, few individuals receive the support they require. This is because there is little guidance on accessing post-diagnostic support, with most autism-specific services focussing on children or adults with more severe needs (Underwood et al., 2023; Huang et al., 2020; Lewis, 2016). Additionally, primary healthcare services are often ill-equipped to deal with autism-specific concerns, while specialist services tend to exclude many autistic adults for not meeting symptom or functional impairment severity thresholds (Griffith et al., 2012). As a result, autistic adults are often left to deal with self-care, social interaction, education, and mental health difficulties on their own (Crane et al., 2018; Baldwin & Costley, 2016; Lehnhardt et al., 2013).

These unmet support needs often persist across the lifespan, regardless of overall cognitive or functional ability. For example, studies have shown that autistic adults are more likely to experience employment difficulties despite having average-to-high educational attainment levels (Harvery et al., 2021; Happé et al., 2016). A survey conducted in the UK among autistic adults diagnosed at a later stage in their life revealed significant unmet support needs related to social skills, housing, and finance (Jones et al., 2014). This prompted the National Institute for Health and Care Excellence (NICE) to warn that autistic adults, particularly those without a co-occurring ID, are at risk of “falling between the cracks” of existing but inaccessible services (Pilling et al., 2012; Barber, 2017).

1.3 Healthcare needs of autistic adults

This warning is especially concerning as studies have shown that autistic adults are five times more likely to experience poor general health when compared to neurotypical controls (Rydzewska et al., 2019). According to research conducted in the US, autistic adults have a higher prevalence of physical health conditions such as diabetes, cardiovascular, neurological, and gastrointestinal issues (Croen et al., 2015). Additionally, they also have a higher prevalence of mental health difficulties, with up to 57% meeting diagnostic criteria for multiple co-occurring mental health conditions (Gotham et al., 2015; Lever & Geurts, 2016). These difficulties persist throughout their lifespan, as shown in a cross-sectional retrospective cohort study of US Medicare data collected between 2016-2017, which found that autistic older adults (n = 4,685) were more likely to experience a range of different physical and mental health difficulties when compared to age-matched neurotypical controls (Hand et al., 2020).

These physical and mental health difficulties often lead to adverse outcomes, with autistic adults having an increased risk of mortality across all ICD-10 diagnostic categories except infections (Hirvikoski et al., 2016). A cross-sectional analysis of emergency department admissions in the US between 2006-2011 concluded that autistic adults were 2.3 times more likely to require emergency care (Vohra et al., 2016). Moreover, a retrospective data analysis using US hospital discharge data from 2004-2014 found that autistic adults had higher odds of inpatient hospital mortality (odds ratio = 1.44) when compared to neurotypical controls (Akobirshoev et al., 2020). These findings suggest that adverse health-related outcomes are not an inevitable consequence of autism but rather represent “unjust and avoidable differences in healthcare access, quality, and outcomes” (Whitehead & Dahlgren, 1991; Bishop-Fitzpatrick & Kind, 2017; Scott & Rawal, 2018, p.1).

1.4 Policies and recommendations

Such health inequalities have prompted the World Health Organisation (WHO) to highlight the needs of autistic adults as a public health concern, recommending that healthcare services

consider autism across the whole lifespan (WHO, 2013). In England, the Autism Act and the Autism Strategy were introduced over a decade ago to make it a legal requirement for services to have an adult diagnostic pathway to improve outcomes across healthcare, education, employment, community support, and the criminal justice system (Autism Act, 2009; Walsh & Hall, 2012). Similarly, the NHS long-term plan, published in 2019, identifies the health and well-being of autistic adults as a critical priority for development over the next decade (NHS, 2019). Several clinical guidelines have also recommended that healthcare services provide autism awareness training to all staff and implement adjustments to meet the needs of autistic adults (Pilling et al., 2012; Buckley, 2017; Nicolaidis et al., 2019).

However, evidence suggests that further efforts to improve training are still required, nearly 40% of GPs report having no training and lack confidence in supporting the needs of autistic adults, with personal knowledge or experience of autism being the most significant predictor of GP autism awareness (Unigwe et al., 2017). These failings have led to the introduction of the Health and Care Act (2022), which legally requires regulated services to provide mandatory learning disability and autism training, such as the Oliver McGowan training to all healthcare staff (Foster, 2022). Additionally, The Lancet Commission has recognised the need to develop "a novel, modified stepped care and personal health model of intervention and assessment" for autistic individuals and their families (Lord et al., 2022, p.271).

1.5 Barriers to accessing healthcare services

To improve healthcare provision for autistic adults, it is helpful to understand their current experiences of accessing support. According to systematic reviews, autistic adults experience various obstacles when accessing healthcare, including at the patient, provider, and system levels (Mason et al., 2019; Calleja et al., 2020; Walsh et al., 2020). Autistic patients may face communication differences, sensory sensitivity, and alexithymia, which is a difficulty in recognising or describing internal states (Mason et al., 2019; Walsh et al., 2020; Doherty et al., 2022). Healthcare providers may lack awareness of autism and fail to provide necessary adjustments or to consider the perspectives of autistic patients and their caregivers (Mason et

al., 2019; Calleja et al., 2020; Walsh et al., 2020). Meanwhile, system-level barriers include stigma around autism, lack of communication between services, and complex or non-existent referral pathways (Vogan et al., 2017; Walsh et al., 2020; Doherty et al., 2022).

According to a survey conducted in the UK among 507 autistic adults, the most significant barriers to accessing primary care support were deciding if symptoms warrant an appointment, difficulty in making an appointment via telephone, and not feeling understood by their GP (Doherty et al., 2021). Similarly, studies on accessing mental health services within the UK found that many autistic adults seek private healthcare due to difficulty accessing mental health services on the NHS as they have long waitlists and limited support (Camm-Crosbie et al., 2019). Moreover, when autistic adults do access mental health services, support is often not tailored to their needs because staff lack autism-related knowledge (Adams & Youngs, 2020). Reducing these barriers is of crucial importance, as negative experiences with healthcare services discourage autistic adults from seeking further support (Nicolaidis et al., 2015).

1.6 Experiences of autistic older adults

The WHO defines 'older age' as 60 years or older, as this is when age-related health problems and mortality rates tend to increase (WHO, 2015, p. 26). In the UK, 'older age' was traditionally considered 65 years or older due to retirement and state pension policies (Rose, 2020). However, this threshold is expected to continue rising due to increasing life expectancy within the general population (Etgeton et al., 2023). In 2019, one in every five individuals in the UK was 65 years or older, and women had an average life expectancy of 83.1 years, whereas men had an average life expectancy of 79.4 years (Morgan & Rozée, 2021). This has led many to state that healthcare services must adapt to meet the needs and challenges of an ageing population (McKee et al., 2021).

Despite an ageing population, only 1% of all autism-related publications in the last decade have focused on older adults (Mason et al., 2022). According to a previous review,

“no study has been identified that specifically addresses older autistic adults’ access to healthcare resources, and no existing studies have included participants over the age of 64” (Sonido et al., 2020, p 73). This is important because older autistic adults might be affected by both non-specific and autism-specific age-related factors (Sonido et al., 2020). For instance, some studies suggest that autistic adults may experience accelerated cognitive decline, while others suggest that they may experience parallel or reduced age-related cognitive decline (Happé & Charlton, 2012; Geurts & Vissers, 2012; Oberman & Pascual-Leone, 2014; Bathelt et al., 2020). Additionally, there is a lack of information on how autistic older adults experience healthcare services despite them having an increased risk of multiple comorbidities and reduced social support (Wallace et al., 2016; Bishop-Fitzpatrick & Rubenstein, 2019).

1.7 Aim of the current study

The current study aimed to explore the healthcare experiences of autistic older adults aged 65 years or over. In-depth semi-structured qualitative interviews were conducted to ask individuals about their experiences accessing healthcare services in the UK. This allowed researchers to explore whether the barriers and facilitators autistic older adults face are like those observed in the general ‘neurotypical’ older adult population or younger and middle-aged autistic adult populations. Given the inductive nature of reflexive thematic analysis, the current study had no specific hypothesis (Braun & Clarke, 2022). Instead, it was hoped that findings would help guide how services could improve experiences, access rates and treatment outcomes for autistic older adults. This is particularly important given the changing healthcare needs of an ageing population. Estimates suggest that there are more than 240,000 autistic adults aged 50 years or over living in the UK, yet services have limited understanding of how best to support their needs (United Nations, 2019; Sonido et al., 2020).

2. Methodology

2.1 Joint project statement

This was a joint project with another trainee (AG) at University College London (UCL). While AG investigated the healthcare experiences of autistic women aged 50 years or over, HM investigated the healthcare experiences of autistic older adults aged 65 years or over, as well as one carer for an autistic older adult aged 68 years with a moderate co-occurring ID (Appendix 1). During the project, the research team (AG and HM) collaborated on the ethics application, online survey, consent forms, participant information sheets, and posters. Although the research team recruited from the same pool of participants who completed the online survey, they conducted separate interviews with different participants and had different topic guides. Due to the word limit and to stay focused on the research aim, the current study will not analyse the online survey data, but this information will be used in future studies completed by MSc students.

2.2 Ethical considerations

The study received approval from UCL's high-risk research ethics committee (22117/001). The official letter giving ethical approval can be found in Appendix 8.

2.3 Setting and recruitment procedure

As a result of the COVID-19 pandemic, all data collection was completed remotely. To accomplish this, an online survey using Qualtrics (www.qualtrics.com) was created. This included a Participant Information Sheet (PIS) and an online consent form (Appendix 9a, 9b, and 9c). The survey consisted of general demographic questions, an autism quotient questionnaire, a health literacy questionnaire, physical and mental health comorbidity questionnaires, and open-ended response questions about healthcare experiences (Allison et al., 2011; Pelikan et al., 2019; Sangha et al., 2003). Participants were recruited for the online survey through third-sector organisations such as the National Autistic Society (NAS), Mencap, Autistica, Pathway Associates, Scottish Autism, and the Autism Partnership Board.

An infographic poster containing a direct link to the online survey and the contact details of the research team was circulated through the networks mentioned above (Appendix 10). In addition, a study-specific social media profile was created to promote the study among autism communities, including local Facebook groups, #AutisticElders, and #BlackAutistics.

A convenience sampling method was used in the project's initial phase to overcome the challenge of having limited time and resources. Upon accessing the survey, participants were asked to confirm that they were UK citizens aged 50 years or above who self-identified as autistic or had an official autism diagnosis. The survey was designed to be completed in one go or over multiple sessions, with an option to save progress. The research team's contact details were made available at the beginning of the survey and in the PIS, which could be downloaded. After completing the survey, respondents could submit their answers anonymously or provide their contact information to enter a draw for one of five £20 One4All gift vouchers. Respondents were also asked if they were happy to be contacted for an in-depth qualitative interview.

Once participants or their caregivers expressed an interest in being interviewed, those who met the inclusion criteria were contacted and sent a separate PIS specific to the interviews (Appendix 11). To ensure the inclusion of underrepresented characteristics, priority was initially given to older participants, identified as female or non-binary and from ethnic minority backgrounds. All participants were given at least 24 hours to read the PIS and ask any questions they had. Participants could complete the consent form independently using Redcap or jointly through a telephone or Zoom conversation with a researcher (Appendix 12). Before arranging a date for the interview, participants were offered the chance to have an informal chat about any adjustments they would like during the interview. Some wanted to be sent the topic guide in advance, while others preferred to split the interview into several sections. During the interview, participants were given the chance to pause or stop at any time, and HM made a concerted effort to ask participants about more general factors that might influence healthcare experiences. This included asking about their journey to receiving

an autism diagnosis, how this impacted their general life, and what impact this might have had on accessing healthcare services. After the interview, each participant was given a £15 One4All gift voucher as a token of appreciation.

2.4 Participants

To take part in the online survey, participants had to meet specific criteria. These included having a formal autism diagnosis or self-identifying as autistic, being aged at least 50 years or over, having adequate communication skills to complete the survey, and having experience with accessing healthcare services in the UK. A separate survey was also made available for carers of autistic adults with a moderate or severe co-occurring ID. It was also important to include those who self-identified as autistic because older adults, females, and those from ethnic minority backgrounds often face challenges in obtaining an autism diagnosis (Huang et al., 2020; Leedham et al., 2020; Pham et al., 2023). A recent population-based cohort study suggests that most autistic older adults living in England are without an autism diagnosis (O'Nions et al., 2023).

The age limit for the online survey was set at 50 years or over as there is evidence to suggest "accelerated ageing" in autism and because this was the cut-off recommended by previous ageing and autism research (Roestorf et al., 2019; Huang et al., 2020). Of the 188 individuals who completed the survey, 133 expressed an interest in taking part in the qualitative interviews, with 27 participants aged 65 years or over. Based on the number of responses to the online survey, HM could purposively sample participants aged 65 years or over. However, it was difficult to recruit participants from ethnic minority backgrounds despite concerted effort, especially in the later stages of recruitment. Whilst there is no consensus on the ideal number of participants to include in qualitative research, 20 participants were recruited. This is well within the range of what is considered appropriate for previous studies to produce sufficient 'information power' when looking at a defined group with a similar research topic area (Hennink & Kaiser, 2022; Creswell & Poth, 2018; Malterud et al., 2016). Please see Table 1, Appendix 13a and 13b for a detailed overview of participant characteristics.

Table 1. Overview of qualitative study participants' characteristics

Characteristics	N
Age range (years)	65-75
Gender	
Male	10 (50%)
Female	7 (35%)
Non-binary	2 (10%)
Other (ungendered)	1 (5%)
Country of residence	
England	17 (85%)
Scotland	3 (15%)
Sexual orientation	
Heterosexual	15 (75%)
Homosexual	2 (10%)
Asexual	1 (5%)
Other	1 (5%)
Prefer not to say	1 (5%)
Ethnicity	
White British	17 (85%)
Any other white	2 (10%)
Asian or Asian British Indian	1 (5%)
Relationship status	
Married	11 (55%)
Single	4 (20%)
Divorced	2 (10%)
Widow	2 (10%)
Separated	1 (5%)
Education level	
Undergraduate	9 (45%)
Postgraduate	4 (20%)
Doctorate	3 (15%)
School-age up to 18	2 (10%)
School-age up to 16	1 (5%)
Did not complete	1 (5%)
Autism diagnosis	
Formal diagnosis	17 (85%)
Self-identify	3 (15%)
Intellectual disability diagnosis	
No	14 (70%)
Self-identify	3 (15%)
Yes (Mild)	2 (10%)
Yes (Moderate)	1 (5%)
Living situation	
Alone	10 (50%)
With spouse	9 (45%)
With partner	1 (5%)
Employment	
Retired	12 (60%)
Employed (part-time)	3 (15%)
Retired Volunteer	2 (10%)
Self-employed	2 (10%)
N/A	1 (5%)

2.5 Patient and public involvement

As part of a larger but separate grant-funded AUDIT_50 project, led by JS and LO, a group of experts-by-experience (EbE) consisting of autistic older adults was formed. The National Autistic Society (NAS) recruited and convened this patient and public involvement group. The EbE group contributed significantly to the project by reviewing all study materials, including posters, consent forms, patient information sheets (PIS), and topic guides for qualitative interviews. Their feedback was invaluable, and they were reimbursed for their time and expertise. Several changes were made to all study materials based on their feedback. For a more detailed explanation of the changes made, please see Appendix 14. The online survey and topic guides were also piloted with EbE members, who confirmed they were acceptable and feasible.

2.6 Data collection for qualitative interviews

Participants were given the option to take part in the interview via telephone or Zoom video call. An encrypted Dictaphone was used to record all interviews to ensure confidentiality. With the participant's consent, Zoom interviews were recorded electronically since the platform has a transcription feature. All recordings and transcripts were securely stored in UCL's Data Safe Haven within 48 hours of the interview's conclusion, and any other copies were deleted. After the interviews, the audio recordings of the telephone interviews were transcribed, and the Zoom transcripts were amended. All identifiable information was removed from transcripts before they were uploaded onto NVivo. For a more detailed explanation of data protection procedures, please see Appendix 15.

Before recruiting participants, a semi-structured interview topic guide based on the primary research aim was co-created with the research team and some EbE members (Appendix 16). This involved developing research questions, identifying potential topics to explore for each question, and formulating related questions in discussions with the broader research team and the EbE group (Clarke & Braun, 2013). The order of the questions were

considered to facilitate rapport-building and to explore potentially challenging topics, such as barriers to healthcare support. Further adjustments to the topic guide were made based on EbE and participant feedback.

Each interview began with a broad, open-ended question about healthcare needs. The interviews varied from 45 minutes to 2 hours, and HM made a concerted effort to foster a relaxed and informal environment that would encourage participants to share their thoughts freely (Roulston, 2010). This involved allowing participants to discuss other topics which were not linked to the questions. Participants were also asked if they would like breaks in between each section and whether they preferred more broad or close-ended questions. There were also regular check-ins with participants throughout the interview to ask if they would like any adjustments or if they were experiencing any issues with regard to the topics or interview length. Importantly, it should be noted that the themes generated in the interviews were co-constructed during the data collection and data analysis stages rather than simply emerging from the data (Braun & Clarke, 2019).

2.7 Analytical approach

A qualitative research approach was used to gain a more comprehensive understanding of the healthcare experiences of autistic older adults.

2.7.1 Ontological and epistemological reflexivity

When conducting research, it is important to consider the influence of our beliefs regarding reality and knowledge. Ontology refers to our perception of reality, which can be categorised broadly into two views: realism, which suggests that there is only one objective reality, and relativism, which argues that there are multiple subjective realities. The approach used in the current study is critical realism, which acknowledges the existence of one reality but recognises that different people or groups interpret and experience that reality differently. On the other hand, epistemology is another branch of philosophy that studies knowledge and how it is acquired. There are various approaches in this field, including positivism, which is linked

to realism and strives for objectivity; post-positivism, which acknowledges objectivity is not always possible; and constructionism, which is linked to relativism and recognises language as a significant factor in knowledge creation.

Similarly, a contextualist epistemological approach was adopted by HM. This considers the context in which language, knowledge, and meaning exist, thereby recognising that individuals cannot be fully understood outside of this context. As such, researchers must take a reflexive approach and consider how their values, experiences, and practices impact data analysis. Unlike positivism, which views data as an objective representation of what individuals have said, contextualism acknowledges that qualitative data needs interpretation to be meaningful. However, it does not go as far as constructionism, where results are presented subjectively based on the researcher's personal experiences. Instead, contextualism utilises the words of participants and allows for the observation of multiple realities without implying relativism. This aligns with a critical realist ontology that views people's perceptions of reality as shaped by their context of being.

2.7.2 *Reflexive thematic analysis*

Reflexive thematic analysis was chosen for the current study because it enables researchers to explore how individuals assign meaning to their experiences while considering broader contexts that shape their interpretations (Braun & Clarke, 2006). This can be approached in two ways: inductive or deductive analysis. An inductive approach was utilised by HM, allowing the production of themes from the data without being explicitly influenced by any specific pre-existing frameworks. Whilst it is impossible to eliminate all subjectivity or personal influences, it was important to acknowledge any perspectives that may have influenced the research throughout the write-up. Semantic instead of latent-level coding was used during data analysis as this focuses on the explicit surface-level meanings of the language used by the participants rather than a more subjective interpretation of what the researcher thinks they might mean.

2.7.3 Data analysis process

The latest recommendations for reflexive thematic analysis were followed with data analysis adhering to the six phases suggested by Braun and Clarke (2022):

1. Familiarisation with the data: To better understand the data, HM conducted all interviews except one and transcribed or amended them by listening to recordings (Appendix 17). To be more critical, HM tried to distance myself from the data and made notes after each interview with key points and impressions.
2. Systematic data coding: HM reviewed two transcripts and compared findings with AG, who also independently coded the transcripts. After this, HM imported all interviews into NVivo, where HM completed line-by-line coding and iteratively changed my coding framework based on the data and research aims (Appendix 18).
3. Generating initial themes: Codes were analysed, searching for "patterns of shared meaning underpinned by a central concept or idea" (Braun & Clarke, 2019, p. 845). Initially, HM felt restricted as he focused on factors hindering or facilitating healthcare access. However, with guidance from his supervisors, HM revised the themes to align with the study's objectives, specifically looking at healthcare experiences.
4. Developing and reviewing themes: HM first mapped and clustered themes before returning to NVivo to read over all the data extracts included in the relevant codes (Braun & Clarke, 2022). By doing this, he could combine overlapping themes and discard those with insufficient depth (Appendix 19).
5. Refining, defining, and naming themes: During this phase, it was helpful to consider the central concept or boundary for each theme and how this contributes to understanding the healthcare experiences of autistic older adults living in the UK (Appendix 20).
6. Writing the report: Each theme and subtheme was populated with relevant extracts from transcripts. HM also incorporated existing literature that provided context.

Although he had some potential names for themes, HM only solidified them once he finished the report and conferred with JS and LO.

2.7.4 Personal reflexivity

My interest in understanding the healthcare experiences of autistic older adults stems from my work within autism diagnostic services. It became apparent to me during this time that there was a significant lack of support available for autistic adults and their families. This resonated with my experience as my mother's primary carer, navigating the NHS and local authorities for the past two decades. As such, whilst neither myself nor anyone in my immediate family has an autism diagnosis, I felt drawn to this project.

I was also mindful of how my preconceptions as an outsider researcher could impact data collection and analysis (Hayfield & Huxley, 2015; Braun & Clarke, 2023). To address this, I conducted bracketing interviews with AG and kept a reflexive journal throughout the interviews. This helped me recognise my dependence on the medical model, which may stem from my experience of coming to the UK as a refugee at the age of 11 and relying on diagnostic labels to obtain support for my family. It also made me acknowledge my tendency to associate ageing and autism with increased difficulties. By recognising this, I approached the interviews with a more open mindset, where I enquired about strengths and resources. I also encouraged participants to elaborate and used summarising techniques to check my understanding. Despite these efforts, it is impossible to eliminate bias. However, I tried to minimise its influence by remaining transparent and aware of my subjectivity.

2.7.5 Quality and trustworthiness

Several guidelines were used to ensure that the study maintained high research quality. This included being “consistent with the philosophical position and aims informing the research methods” (Fossey et al., 2002, p. 273). The study also referred to the following four broad principles for demonstrating validity in qualitative psychology (Yardley, 2000; Yardley, 2017):

Sensitivity to context: Following Yardley's (2000) recommendation, a review was conducted on the relevant literature to help situate and contextualise study findings. In addition, HM remained aware of his outsider position (see personal reflexivity section) and tried to create a safe and non-judgmental space for participants (Clarke & Braun, 2013).

Commitment and rigour: During the research process, HM demonstrated commitment by carefully selecting the study's methodology, adhering to the most current reflexive thematic analysis guidelines, and working closely with co-researchers and an EbE group (Braun & Clarke, 2022).

Transparency and coherence: HM ensured transparency by clearly explaining the study design, data collection, and analysis. Additionally, he acknowledged his personal and epistemological influences. Direct quotes were included to ensure transparency, with themes coherently building on one another.

Impact and importance: Findings provide valuable insights into the healthcare experiences of autistic adults aged 65 years or over. This can help service providers, clinicians, and policymakers improve services.

3. Analysis

Reflexive thematic analysis was used to identify four primary themes, with 15 sub-themes (See Table 2). Themes were arranged sequentially, so they build on from one another. Theme one describes how lived experience predisposes healthcare access challenges, theme two highlights the impact of system and service-level changes, and theme three introduces the intersectionality between ageing and autism. Finally, theme four discusses key recommendations made by participants for policymakers, healthcare services, and healthcare staff. Quotes were chosen to evidence patterning, with at least one quote from each participant being included (Braun & Clarke, 2022). Ellipses […] denote omitted sections from the interviews, and text within square brackets [text] provides context when needed. Please note that key reflections based on the overall quotes and themes are reported in the discussion

section. Therefore, the analysis section will have minimal input regarding general reflections as HM felt it was important to maximise the number of quotes included so that participants' own words will be used to tell their stories.

Table 2. Overarching themes and subthemes

Theme 1. Lived experiences that predispose access challenges
1.1 Feeling vulnerable and experiencing adversity since childhood
1.2 Lifelong anxiety with limited mental health support
1.3 Stigma and lack of post-diagnostic support
1.4 Impact of lived experiences when accessing healthcare services
Theme 2. Impact of system and service-level changes
2.1 Feelings of burdensomeness due to pressure on services
2.2 Healthcare services moving online
2.3 Frustration with waitlist delays and uncertainty
2.4 Reduced empathy partly due to high staff turnover
Theme 3. Intersectionality between ageing and autism
3.1 Anxiety, alexithymia, and social communication difficulties
3.2 Sensory difficulties reaching 'overload'
3.3 Hopes and fears about the future
Theme 4. Policy and practice recommendations
4.1 Importance of policy, training, and research
4.2 Identifying and mitigating unmet support needs
4.3 Recommendations for healthcare services
4.4 Recommendations for healthcare staff

Theme 1. Lived experiences that predispose access challenges: vulnerability, anxiety, stigma, and self-doubt

The first theme highlighted how participants' lived experiences of growing up in an era when autism was little recognised shaped their lives, leading to low self-worth, mental health difficulties, and misdiagnosis. Participants described how current misunderstandings about autism perpetuate stigma and adversity.

1.1. Feeling vulnerable and experiencing adversity since childhood

Participants, who had varying degrees of autism characteristics, shared that they have always felt different:

> *"I wasn't diagnosed as a child which you should be these days. And I wore a mask and I suffered the abuse of the world. Everybody thought I should be normal." (P2)*

These experiences were made worse by the fact that no one recognised that they were autistic, meaning that they often experienced negativity from others:

> *"I often, in childhood, felt very vulnerable. And very as if I was being a nuisance. In fact, was frequently told I was a nuisance." (P7)*

This led to participants being targeted across a range of different contexts:

> *"It starts in the family, I think if you're disruptive to the family, then you'll feel disruptive to every situation you find yourself in after that. […] One of my teachers was disciplined for the extent of bullying to try to make me be like other children." (P19)*

1.2 Lifelong anxiety with limited mental health support

As a result of feeling vulnerable since childhood, most experienced anxiety and depression:

> *"Life was very stressful. It just seemed like, although I was successful in my career, I was living this pretence, and it was so draining, so tiring, so stressful. And I think that's where the depression came from, and still these feelings that you're not the same as everybody else." (P8)*

One participant highlighted how anxiety was something chronic:

> *"If you live in a world which makes you anxious all the time, it's not a mental health problem. It's just who you are." (P7)*

Unfortunately, mental health needs often remained unmet, with support varying across areas:

"The local health service authority has dismissed me from the mental health department three, maybe four times without explanation. […] It feels to me like the whole mental health department in [Local Area], or at least [Local Hospital], has completely collapsed." (P14)

Even when accessing healthcare services, autism would often remain misdiagnosed:

"This particular psychiatrist, I had more hopes on, but it didn't go well at all. He didn't understand me at all, and misdiagnosed me with a personality disorder, which I understand is quite common in adult women who have got autism." (P3)

This meant that participants were frequently placed on medication for longer than required:

"I've been on almost every tablet you can imagine over the last 20 years. And, unfortunately, I'm still taking the tablets. I would like to come off them to see how I actually am without medication because my realisation that I'm autistic answers 74 years' worth of questions." (P2)

1.3 Stigma and lack of post-diagnostic support

Most participants found the autism label to be a helpful explanation for their difficulties:

"I've had 30,000 questions as to why my life has been hell and the word autism came into my head. I have no idea how or why, but my wife had just died and perhaps she told me. But it suddenly answered those 30,000 questions." (P2)

However, receiving a diagnosis in later life was also associated with mixed emotions:

"Because my diagnosis was so late, there's some part of me that still thinks I can make everything all right and just be normal. […] It's useful to know that I'm autistic and I can work with that, but I've still got a resistance to it as well." (P9)

These emotions were made worse by the stigma associated with autism:

"However well you know someone, it always affects, it seems to affect how they behave towards you. […] It's just as though they think you're somehow not quite all there." (P9)

For this reason, many participants were reluctant to share their autism diagnoses with others:

"I haven't told my mother. I haven't told my sister. I haven't told the people at work. And the reason for that is, it's because I don't feel safe to do that." (P16)

Similarly, participants shared that there was little to no post-diagnostic support:

"No support whatsoever. And I think it made me feel like I had to look at my life. I had to review my whole life through the lens of autism. And, I don't know, you're very confused. […] You're just left with all those feelings that you don't know what to do with them." (P16)

1.4 Impact of lived experiences when accessing healthcare services

This lack of understanding and support around autism was also present within healthcare services:

"And part of it is that people [including healthcare professionals] don't understand the breadth of autism […] Like the way that you can be really normal seeming in their eyes and then really are very distressed about certain things" (P10)

One participant shared what it felt like to have an autism diagnosis on her healthcare records:

"At the time I had an eating disorder, anorexia, on my notes. And that's always a stigma, people always look at you as if you're a piece of rubbish. Of course, they now look at me as double rubbish because I'm autistic and I've got an eating disorder." (P3)

Participants also spoke about how past experiences impact current interactions:

"I've also got effects of trauma from emotional abuse as a child and then a more recent thing when I lived in the community for a while. […] So, I think I find it quite difficult to

trust people and feel comfortable, you know? […] Because I think I feel I won't be taken seriously." (P9)

These experiences were often repeated when accessing healthcare services:

"That's my life. That's being autistic. That's what being autistic is and that's why it's a disability. And you know that you've got no hope of communicating that, but that's, basically, what being autistic is. So, your experience in the hospital is just exactly the same as your experience anywhere else, basically." (P19)

Theme 2. Impact of system and service-level changes: reduced resources, services moving online, increased waitlist uncertainty, and high staff turnover

The second theme considers the impact of the current economic situation on healthcare services which have had to change the way they function. As a result, it has become more difficult for participants to access support with longer waitlists and high staff turnover, leading to a general feeling of reduced empathy.

2.1 Feelings of burdensomeness due to pressure on services

In addition to the impact of lived experiences when accessing healthcare services, all participants spoke about increased pressures and reduced resources placed on services:

"I know my practice must be so overworked in terms of the GP-to-client ratio. They just don't have the time or resources to do what they might have done in the past. […] They were more proactive. Now, if you're lucky, they're reactive." (P17)

There were even concerns about receiving support in an emergency:

"You can't even get a 999 ambulance now quickly unless you're not breathing. […] I heard someone yesterday who phoned for the ambulance because a person had collapsed and stopped breathing. […] It took 37 minutes to come and so she was dead." (P18)

As a result of the above pressures, most felt reluctant to access services:

> *"But they also do sometimes make you [feel like a burden]. I felt I was taking away a bed from someone. […] I don't go to the doctor unless I think it's really urgent or really necessary." (P4)*

Similarly, even when participants did access services, they expected sub-optimal care:

> *"I have to be in a fairly needy position before I'll even contemplate a GP, but, when I do, then there's that part of you thinking he's not really going to give me the time that I need, or is he going to fob me off, here, take these tablets, and see me in two weeks?" (P8)*

One participant highlighted a general feeling that older adults were not seen as a priority:

> *"Sometimes it feels like if you're above a certain age, your health doesn't, it's not that it doesn't matter but it's not as important as if you're young." (P16)*

2.2 Healthcare services moving online

To manage demand, services have moved online with participants highlighting some benefits:

> *"Now I can put a request in [to my GP], that I can think about, as an email. And somebody will get back to me, as an email, and then I can think about it a bit, and then I can get back to them. So, in a sense, that builds in the pauses. That is more helpful for me." (P13)*

However, there were concerns over complicated hospital booking systems:

> *"They do things like send me an appointment letter, and then they send me another appointment letter, and it wouldn't say we're cancelling the previous appointment. […] So, I wouldn't know if I had two appointments or what. Then, I'd ring the number of the thing, and they'd say it's not us, it's someone else." (P19)*

Similarly, whilst some liked online consultations, the vast majority preferred face-to-face:

"I like to be able to see all the body language that I can get because I have noticed that a lot of people, you need to look at their body language, and not listen to what they say. Because body language and what's coming out of their mouth don't always coincide." (P7)

This was also because face-to-face consultations allowed for extra support:

"If I'm talking to somebody and they don't get what I'm trying to say, I can literally go from nought to 20, and panic. […] Whereas if I was seeing them face-to-face, they could just say a few calming down things." (P3)

2.3 Frustration with waitlist delays and uncertainty

Participants also spoke about increasing waitlists for treatment which could greatly improve their quality of life:

"Everything takes two or three years at the moment. […] I had my fusion, which is causing me severe back pain at the moment. And I've also got arthritic hips, okay. I was supposed to see somebody about that but my GP said don't expect to see anybody for over two years." (P15)

There was also a feeling that healthcare services have become more closed off:

"I'm trying to chase up my appointment at the hospital for the surgery and I've tried phoning and they say they'll get back to me and they don't. I've tried emailing. Nobody gets back to you. […] That in itself can make you say, well, give up or, what's the point?" (P4)

With some services even refusing to provide any updates on waiting list times:

"At one stage, months ago, I said, how long is the waiting list now? Because you used to say two years. And they simply said, oh, we've stopped telling people. […] So, oh well, can you give me any indication at all? Three years? Four years? When I'm dead?" (P14)

This lack of communication was particularly frustrating as it led to increased uncertainty:

> *"As you get older, you become aware that you want to make the most of your life. The most of your time, really. And this constant waiting for things that you hope are going to improve your quality of life is really quite frustrating. […] I'd much rather know whether it's two months or two years because it's not knowing. And I find not knowing things really, really hard." (P9)*

One participant shared how anxiety-provoking it can be to even receive a call from his GP:

> *"[Getting a call] is obviously very difficult for me because I then am in anxiety all day until they phone back. […] Is my phone working? Is the internet working? […] When the phone rings and it's not her, my heart is racing. And then when she's speaking to me, have I said everything? Have I remembered everything I needed to say? Did I say it in the right order?" (P11)*

2.4 Reduced empathy partly due to high staff turnover

Participants also noticed that it has become more difficult to form relationships with staff:

> *"In the surgery that I went to [in the past], it was easier to have a relationship with the doctors and nurses who were there, because it was all much more stable" (P7)*

This high staff turnover caused increased levels of anxiety:

> *"It's a bit harder with a [high] turnover of staff because, with a person who you've had quite a lot of dialogues with, there is some residual knowledge that they have of you." (P5)*

Seeing someone new also meant that it was more difficult to receive personalised care:

> *"I've had to go back three times [for blood tests], and they've said, oh, we haven't got an appointment for two weeks and I'm absolutely terrified for two weeks, and I mean terrified and in a state, meltdowns, everything [...] And my GP that I had before*

wouldn't have done that. It's only two minutes or five minutes, whatever, per appointment. So he would put me in somewhere the next day." (P6)

One participant who was a carer for her husband with a learning disability highlighted the importance of her husband's trust in professionals:

"The last time we had to move because of how the GP was towards him. But we're trying to see one consistent GP now because it makes his life a bit easier. […] Because then he trusts them. Sometimes, he doesn't trust them. That they don't understand him, and they're not making reasonable adjustments or are not understanding of his complex conditions." (P20)

This lack of continuity of care is particularly disruptive as many participants have faced a lifetime of mismanagement by services:

"My GP retired. Now it's absolutely tragic […] she was the first person that ever made us feel positive, or less negative about our eating disorder. […] She said, you do know that an eating disorder's not your fault, don't you?" (P3)

As a result of these changes, there was a sense that services have become less empathetic:

"It feels as if the whole system's become very mechanical compared to what I used to have in the past. […] The whole world really, the medical thing included, has just become… Well, it's not just me. It's less empathic, I think." (P14)

Theme 3. Intersectionality between ageing and autism: communication difficulties, sensory overload, and worries about the future

The third theme focuses on the intersectionality between ageing and autism. Participants reported similar difficulties when accessing services as those observed in autistic younger and middle-aged adults but there were also some nuanced differences.

3.1 Anxiety, alexithymia, and social communication difficulties

Even before healthcare services became 'less empathic', participants had generally found it difficult to access support:

> *"That worry of not knowing. So, you go to the GP, or if you go to hospital, what's going to happen? I don't know what they're going to do to me. […] It's new surroundings, new people. All those things add to your overall overload and anxiety." (P8)*

This might be because some participants struggle to verbally communicate internal states ("alexithymia"):

> *"I have these feelings, or I'm aware of a feeling, but I can't tell you what it is. So, say imagine if you go to the doctors, how are you feeling? What does that mean? I don't know what that means." (P16)*

Differences in non-verbal expressions also makes it difficult to communicate severity:

> *"You can see they're [non-autistic people] in pain, but you can't see I'm in pain because our faces could be the same for happy things or sad things or whatever, so we don't show the emotions. So they don't get how bad you are." (P6)*

All the above exacerbates social communication and cognitive processing difficulties:

> *"If I'm talking to a doctor I've got this mental list of things I need to say […] And I often forget, sometimes, even the most important things, I forget to say. Because it's like I get confused if I feel under any kind of pressure." (P9)*

Some reflected on how these processing difficulties might also be impacted by ageing:

> *"But obviously from a mental point of view, your brain slows down a bit. […] You can't always retrieve the words that you want from your brain. It's there, but you can't always retrieve it. But I think that happens a lot when people get older." (P16)*

To manage, one participant reduced the amount of information she shared with staff:

"You can say a couple of things because you don't want to tell them loads because you feel like you're a nuisance, so you can tell them a couple of things because you don't want to bring everything up in one go." (P6)

Others practiced what they might say in advance or engaged in mindfulness techniques:

"I practice in my own mind what I'm going to say, before I get into a conversation with the medical professional […] I would always try and pause before I respond, because that gives me just a little breath." (P13)

While these strategies were helpful, they also added an extra level of pressure:

"When you're all revved up to say what you want to say, and you walk in [the doctor's room], and they go I'm just looking at your notes. So your impetus has gone. This is wrong. It shouldn't have happened, because it wasn't in your rehearsed pattern." (P7)

3.2 Sensory difficulties reaching 'overload'

In addition to anxiety, alexithymia, and social communication difficulties, participants also spoke about how overwhelming it can be to navigate healthcare services:

"One person said [bring] earplugs and an eye mask [to the hospital]. And I thought I won't need those. But I really should have taken them with me. Because there was so much noise all the time and people talking and lights on. And awful smells of the polish and the food they were cooking for every meal." (P10)

Sensory difficulties were not just limited to the environment but could also impact certain procedures:

"Some of them [health professionals] use that disinfectant wipe or whatever it is to put on your arms when they do blood tests. That can put me in one [a 'meltdown'] because that's too strong and that's right by me." (P6)

These factors might be difficult on their own, but when combined, they can stop participants from being able to process what is being communicated:

> *"Have you come across the Spoon Theory? That you have so many spoons of energy per day, and that each thing that you have to do uses a spoon. Basically, all those spoons are gone in coping with the lighting, getting lost, being worried about getting lost, being worried about doing the wrong thing, all that. You're not even listening when they tell you you're going to die [from cancer]. You take it very well because you haven't really understood it." (P19)*

Sensory, social communication, processing, and mobility issues can also combine and feed into each other:

> *"[Upon entering the hospital corridor] you start spinning around, making noises. Going into meltdown because of all the people there and the noise and smell. And then if I ask someone directions, they give you three or four ways to go up the lift and God knows what, and I can only remember the first one. And then I can't go in a lift on my own and it was upstairs. You had to go in the lift. I couldn't have gone up all the stairs. […] So I just ended up not being able to drop it [urine sample] off, going into meltdown, and leaving." (P6)*

3.3 Hopes and fears about the future

When asked about the impact of ageing, most participants highlighted that it was associated with increased health difficulties and reduced energy levels:

> *"I am getting older, and your health does actually I think deteriorate a bit as you get older, actually. I find that I am less resilient than I was, but that is manageable. And you just take it on board and think, okay, I'm likely to get a little bit more tired." (P13)*

Importantly, there was also a sense of increased self-acceptance and understanding of difficulties:

"I found, as I aged, that it's become more and more exhausting. I feel like standing on a table and saying look, I'm autistic, you idiot. And I cannot do what you're asking of me. But I have learnt to do things like when I know that something will be too much, to just say no, I'm sorry. I can't do that." (P7)

One participant spoke about her hopes for society to be more accepting of autistic elder:

"This often doesn't happen, especially in our sort of society, but I like the idea of elders, wise people. […] And you go to older people for advice." (P9)

Despite ageing being associated with positives, there were also concerns particularly around social isolation:

"We, mostly, have fairly tortured relationships with our families who regard us as a burden. We, usually, have quite small circles of friends. A lot of us are married, but a lot of us aren't. And a lot of marriages break down and a lot of us are non-binary which adds an extra layer to it. And I think it is extremely worrying contemplating where autistic people are going to be when incapacitated. We cope by hiding, but hiding's not going to work if you're incapacitated." (P19)

These concerns were especially elevated when considering the impact of age-related decline:

"When I'm more elderly and less able, mentally and physically, now my life is in somebody else's hands to a degree. Now, if that person that's looking after me […] they are not autistic aware or haven't had training […] I'm just going to be their worst nightmare, aren't I? […] If you try to just make me do something I don't want to do, I might not have the capacity to be able to explain to somebody, I don't like this because of the noise, or, I don't like this, stop touching me. […] If I haven't got the capacity to do that, well, that's me locked into hell." (P8)

Theme 4. Policy and practice recommendations

The fourth theme introduces key recommendations made by participants. There was a sense that more needs to be done to provide support for autistic older adults living in the UK. Key recommendations included the need for more consistent policies and training as well as the need for services to identify and mitigate for unmet support needs. Similarly, participants highlighted how small adjustments can make a big difference to their overall experiences.

4.1 Importance of policy, training, and research

Participants spoke about the need for more training and guidelines for healthcare staff:

> *"But I think there's very little awareness in healthcare about autistic needs. […] Because I know, obviously I've worked in healthcare since 1975 and I've had no training about autistic needs or no training about looking after patients that are autistic. And I know GPs, what do they get? About an hour?" (P16)*

Identified knowledge gaps included the impact of adversity on autistic people or those with co-occurring learning disabilities:

> *"I don't feel people understand learning disabilities, and I don't think people understand autism, and I don't think people understand trauma and the impact of it on people with learning disabilities." (P20)*

There was also a sense that autism falls between the gaps in terms of service provision, with different policies across different boroughs:

> *"In some parts of the country, they put you [autistic people] under mental health but in our part, you're put under learning disability but if you need a counsellor or anything, you're not allowed to use their resources if you haven't got the learning disability as well. So you're in no man's land." (P6)*

This lack of consistency in policy or service provision can lead to difficulty accessing support:

"My youngest son was diagnosed with Asperger's when he was 12. My wife observed that I have similar traits, and so I went to the GP and asked for a referral. It took six years and a change in the law, because they said that if you have learning difficulties, then you could be assessed." (P12)

One participant noted the impact of policy change on their overall experience:

"The 2010 Equalities Acts that's just transformed my life completely. […] They can't openly discriminate against you. You can just tell them, and that takes a lot of the problem out of it." (P19)

Another spoke about the need for more autistic people to be directly involved in service design:

"[Services need to] learn from us, […] for us to be able to tell you what we need, or what we would perhaps like going forward, what works, what doesn't. […] We are going to need more healthcare needs. It just comes with age, doesn't it? But if it's not provided in the right way, it becomes a problem in itself." (P8)

4.2 Identifying and mitigating unmet support needs

Other key recommendations made with regards to the impact of ageing is for services to identify whether an individual has any support structure:

"Older autistic people might be more isolated than older typical people. And so therefore it's kind of important [for healthcare services] to see the whole person and not just the medical condition […] there may not be the same support that a typical person would have in terms of family." (P1)

This was particularly important as participants highlighted the lack of health or social care services available to autistic adults:

"I've had no help. I still don't get any help. The only help I get is the stuff that I get from people I found on Zoom, from autistic groups. That's the only help I get. And knowing that I'm not alone and there are other people out there." (P2)

For this reason, some participants recommended that autism-specific support from health or social care services would be important:

> *"I think that some people might just need someone else to help them. Somebody who understands their autism, understands their medical needs and who is able to communicate with these different agencies." (P1)*

One participant suggested that this could take the form of check-in calls:

> *"If just someone [from the GP surgery] could [make contact by phone]. Not all the time but just now and again, check in and it's, how are you doing? Have you got any problems? Is there anything, we need to send you to help you? That sort of thing would be brilliant because then you don't feel as though you're being a nuisance." (P9)*

Participants also identified a need for support groups to link them with other autistic people:

> *"I just wish there was another group of elders on the spectrum to share this rubbish with. […] When I had more energy, I was getting to the stage, well, okay, I think I'll try and initiate an elders' group for people probably who've been high achieving and have had a job and are feeling a bit lost in retirement." (P14)*

Similarly, the one participant who was a carer identified the need for services and staff to include carers in the decision-making process:

> *"They've got to include us as a carer and us as a family member because where they mask, and they're not getting the true picture, at least we can include it." (P20)*

4.3 Recommendations for services

There was also a sense that services were "designed for someone who is not me" (P19):

> *"The services that are organised are very much organised for neurotypical people, I think, and autistic people don't fit in very easily and they go round in circles." (P18)*

One key recommendation was for services to become more sensory friendly:

"Colour. Bright neon is not good. Bitty, deeply contrasting patterns are not good. Too many vocal announcements over loudspeakers are not good. It just adds to the sensory overstimulation." (P13)

If this is not possible, then it would be important for services to provide a quiet space:

"I suffer from sensory overload, I would like that to be sorted out. A facility where I can be kept quiet, no bright lights and people rushing around in front of me. Ideally, to be put into a single room […] shielded from the rest of the noise." (P2)

Similarly, participants highlighted the need for more regular updates from services:

"Just general communication about what's happening. Like, maybe, just sending a quick email […] saying, oh, you're now here on the waitlist. Just to feel they're keeping in touch with you and they know you're waiting." (P9)

This included the need to improve telephone booking systems:

"But they need to make it easy for you to cancel it if you can't make it as well. And they don't. Because you can spend half your lifetime and not get through to them to cancel an appointment." (P17)

To make appointments less stressful, participants suggested that it would be helpful for services to run on time or at least have regular updates:

"If they can't keep to time, have an update more or let you know how many people are in front of you or something. If you know what's happening, it's easier." (P4)

Finally, participants highlighted the importance of ensuring continuity of care:

"As soon as they see […] on your records, on your piece of paper, a little autism sign or something. […] That they go, oh yes, click. Oh right. Now I need not just to refer to the last GP's notes […] I need, for this guy, to see the same person every time. And this never happens." (P14)

One participant gave an example of how this could be achieved through better communication between services:

> *"I told the ambulance crew that I realise I needed treatment for autism and they did contact the hospital before we got there and they did arrange for me to be put in an end-bed in as quiet a place as possible. So, the hospital knew that I was using these aids for self-survival, so they were happy with that." (P2)*

4.4 Recommendations for healthcare staff

A key recommendation made for staff was to check for adjustments right from the start:

> *"So I think it's really important for each person with autism just to be aware of what their particular needs are in any given situation. And for the person on the other end just to be aware of that and make allowances." (P1)*

There was a general acceptance for the idea of a hospital passport where participants could write their needs on a document which they can carry on their persons before accessing services:

> *"I think they're a good idea, because at least it gives the people in the hospital some idea that you are different and might need different things." (P7)*

Regardless of needs, all participants highlighted the importance of reassurance and empathy:

> *"If I say, I'm autistic and I also have anxiety, they say okay, anytime that you feel you want to stop. […] The ones that are genuine, they will, whatever they're doing, they'll say, is this, okay? Is that okay? I'm just going to hold your hand, they will explain to you, I'm just going to read your pulse here." (P11)*

This was particularly important when considering communication and processing differences:

"Well, I think the priority has got to be understanding communication. Realising that the communication is different, and I think, like you mentioned earlier, it takes us a little bit longer to process things." (P16)

As such, there was a preference for staff to use simple language and to check understanding:

"I think that's really important because so often, they just rush on from one thing to the next. And I've completely lost them by the time they've finished because my brain can't keep up with that speed." (P9)

It was also important for staff to allocate extra time and to use visual or written cues:

"Just ask questions that make you more comfortable and just really give you more time to answer and try to put things in writing or pictures as well as what they're trying to tell you." (P6)

One participant highlighted how visual cues helped him better understand his condition:

"I've got this chronic long-term back pain […] And I said to her [community physiotherapist] […] if I can see something I can make a lot of sense around the areas of my pain. And she said give me your phone I'll just transfer the X-rays. And do you know what that was so helpful because I had something a picture which I could relate to. […] I could understand why I get pain in a certain place and why certain movements would trigger it." (P15)

Similarly, healthcare professionals could alter their questioning style to help aid participants:

"I find it easier that you can answer a direct question, not… almost yes or no, or does this hurt? Does that hurt? Or do you find it here? Rather than me trying to explain what hurts. Sometimes, short, bullet-type questions for someone like me, which I think they want to avoid usually." (P4)

Finally, knowing what to expect and having consistency of care was also seen as important:

“This last doctor [I saw in A&E] was absolutely amazing and just hit the nail on the head really with regards to what I needed in terms of information, in terms of having a named person, I think that's important. Seeing your care through to the end and giving you some idea about how long you'd have to wait in each department and just that reassurance which was just so important.” (P1)

4. Discussion

The current study explored the healthcare experience of autistic older adults living in the UK. It is the first study to focus on the healthcare experiences of autistic adults aged 65 years or over (Sonido et al., 2020). Reflexive thematic analysis was used to co-construct four themes, which highlighted "lived experiences that predispose access challenges", "impact of system and service-level changes", and the “intersectionality between ageing and autism”. The fourth theme concludes with key “policy and practice recommendations”. Whilst some of the findings were consistent with previous research on younger and middle-aged autistic adults (Mason et al., 2019; Calleja et al., 2020; Brice et al., 2021; Doherty et al., 2020), they also introduce new perspectives and insights that can be used by healthcare services, staff, and commissioners to provide better care for this under-served population.

4.1 Lived experiences that predispose access challenges

The first theme explored how lived experiences predispose autistic older adults to healthcare access challenges. Like previous studies, participants spoke about being targeted and blamed for things their whole lives (Pearson et al., 2022; Ratto et al., 2022). As a result, many felt vulnerable, different, and anxious since childhood, and went on to develop mental health difficulties. The lack of awareness of the heterogeneity of autism exacerbated these difficulties. Participants were often left to manage their mental health difficulties on their own, with services often discharging or misdiagnosing participants. Whilst there has been an improvement in our understanding of autism, many autistic adults still do not have access to mental health support (Camm-Crosbie et al., 2019; Nicolaidis et al., 2013). A recent study has found that receiving

a later autism diagnosis (21 years or older) was associated with increased mental health difficulties (Jadav & Bal, 2022).

This is somewhat reflected in the interviews from the current study, with many participants embracing their autism label as a positive aspect of their identity, which helps them to make sense of their difficulties (Huang et al., 2021; Powell & Acker, 2016; Hickey et al., 2018). However, for some, the diagnosis also came with mixed emotions, mainly as they had lived their whole lives not knowing that they were autistic and trying to fit in. As previous studies have found, all participants stated there was little to no post-diagnostic support (Underwood et al., 2023; Lewis, 2016; Crane et al., 2018). This is particularly concerning as some participants have not shared their autism diagnosis with others due to societal stigma. Participants also shared that a general lack of understanding around autism was common in healthcare services, which meant that their previous lived experience difficulties were often replicated with healthcare staff, making them feel blamed for things and not understood.

4.2 Impact of system and service-level changes

In the second theme, system and service-level changes emerged as important factors that influence the healthcare experiences of autistic older adults. Several studies have highlighted the impact of system and service-level factors on the experiences of autistic younger and middle-aged adults (Vogan et al., 2017; Mason et al., 2019; Walsh et al., 2020). However, none have looked at the impact of these changes on autistic older adults, particularly post-pandemic. All participants expressed concerns about the increased pressure on healthcare services and reduced resources, which have led to services becoming less proactive. Even when participants did access healthcare services, there was a general feeling that the healthcare needs of older adults were not seen as the priority. As such, most felt reluctant to access services unless their condition was severe, as they did not want to waste resources.

To manage increased demands, services have had to move online, with many participants stating that it has been helpful to be able to contact their GP through an email or text message. However, as reported in previous studies, there were concerns over complicated booking systems (Cummins et al., 2020; Lipinski et al., 2019). Most participants also stated that they preferred face-to-face over telephone consultations as it helped reduce the opportunity for misunderstanding, and it also meant that they could receive extra support if they experienced anxiety during the interaction. Despite some positives associated with healthcare services moving online, there were also concerns about who might be left behind, especially when thinking of people who might not have access to technology or who might not feel comfortable navigating these new systems.

Another source of anxiety for all participants was the increased waiting list times and reduced updates from services. This extended waiting period left participants feeling isolated and forgotten by healthcare services. All the above, coupled with clinicians retiring and high staff turnover, have led to a general feeling that healthcare services are becoming more 'mechanical' and 'less empathetic'. In fact, a recent qualitative study on the healthcare experiences of autistic younger adults highlighted a consistent patient-provider relationship as a critical factor in improving levels of trust, familiarity, and personalised care (Mazurek et al., 2023). This was also reported by many participants, who stated that seeing someone who knows them reduces their levels of anxiety, particularly when seeking support for more complex healthcare issues.

4.3 Intersectionality between ageing and autism

Consistent with previous literature, autistic older adults experience the same autism-related difficulties when accessing healthcare services as autistic younger or middle-aged adults (Mason et al., 2019; Calleja et al., 2020; Walsh et al., 2020). However, the third theme also highlights the intersectionality between ageing and autism. As such, most participants reported experiencing anxiety when accessing healthcare services as it is often a new environment with new people. This anxiety can impact social communication and cognitive

processing difficulties, which might also increase with age. Similarly, some participants also struggle to answer questions about their internal state due to alexithymia, which is common in autism regardless of age (Bird & Cook, 2013). To manage, many participants engage in compensatory strategies such as limiting the amount of information they disclose or practising what they might say in advance. Whilst these strategies mask difficulties, they also increase cognitive load, making it more difficult to remember the information discussed (Livingston & Happé, 2017).

When accessing healthcare services, participants frequently face sensory difficulties, which can lead to sensory overload. This can be made worse by ageing, where participants might have less energy to manage sensory overload. These difficulties were not just limited to the environment but could also occur during certain medical procedures (e.g., MRI scans, physical touch, difficulty swallowing tablets, and staff using disinfectant or latex). Whilst some of the current findings replicate those observed in other studies, there was a sense that autistic older adults might have more complex and longer-lasting healthcare needs, which exacerbate difficulties (Mason et al., 2019; Walsh et al., 2020; Hand et al., 2020). As such, mobility issues, reduced social support networks, and age-related issues, such as reduced energy and more complex healthcare needs, can all act as barriers to healthcare access. These difficulties can feed into one another and exacerbate healthcare access difficulties, particularly if there is no support.

Despite these barriers, participants also associated ageing with increased confidence, self-acceptance, and understanding of their difficulties. This meant that most participants felt they had the experience and confidence to communicate when they might be struggling. It also led many to understand better what tasks they could or could not complete. However, despite these strengths, participants also discussed worries about receiving adequate care, particularly if they have limited social support networks. These concerns were made worse when contemplating the impact of age-related cognitive or physical decline, which could impede their ability to advocate for themselves or to convey their preferences effectively.

4.4 Policy and practice recommendations

Whilst the previous themes focused on the healthcare experiences of autistic older adults, the final theme introduced key recommendations made by participants. Consistent with prior research, participants emphasised the need for improved training and guidelines for healthcare staff to enhance their understanding of the heterogeneity of autism (Pilling et al., 2012; Buckley, 2017; Nicolaidis et al., 2015). They also identified gaps in knowledge related to the impact of communication and sensory sensitivity on autistic individuals and those with co-occurring learning disabilities. Additionally, participants pointed out inconsistencies in policies and service provision across different regions, which can hinder access to funding and support. Recommendations included increasing the involvement of autistic individuals and their caregivers in service design and creating more consistent autism policies.

Most participants also emphasised the lack of health and social care services available to autistic adults, particularly in older age (Crane et al., 2018; Baldwin & Costley, 2016; Jones et al., 2014). For this reason, it was recommended that healthcare services assess the support structures available to autistic older adults, who may be more isolated than their neurotypical peers (Wallace et al., 2016; Bishop-Fitzpatrick & Rubenstein, 2019). Recommendations included creating specialised support services tailored to the unique needs of autistic individuals. Participants also discussed the importance of regular check-in calls by general practice staff to assess healthcare needs. Additionally, support groups connecting autistic older adults can provide much-needed social connections to share experiences and resources.

Regarding current healthcare services, participants noted that they were not designed with autistic people in mind. As such, recommendations included making healthcare environments more sensory-friendly and providing quiet spaces when necessary. In addition to sensory adjustments, services were recommended to provide more structure and routine as this can help reduce anxiety (Hwang et al., 2020). This can be achieved by having regular updates about waitlist times, improving telephone booking systems, and running appointments

on time or with more efficient scheduling updates. Whenever possible, continuity of care with the same healthcare professional was also highlighted as essential for building trust and maximising personalised care. Where this is not possible, then it would be important for healthcare services and staff to communicate with one another so that the onus is not always on autistic older adults to adapt or manage without any support.

When it comes to healthcare professionals, it would appear as though small adjustments make a big difference. As such, staff should check for adjustments based on individual needs and preferences. Empathy and reassurance were emphasised as vital components of healthcare interactions. Summarising, using simple language, and allocating additional time were key adjustments to help reduce anxiety and improve comprehension (Slater et al., 2020). Some also highlighted the importance of using visual or written aids, with one participant stating that she prefers close-ended or more direct questions when it comes to symptom explanation. Moreover, familiarity and knowing what to expect during and after the healthcare consultation were deemed essential to receiving good quality care. A summary of key recommendations and suggestions made by participants can be seen in Table 3.

Table 3. Key recommendations and suggestions made by participants

Recommendation 1	**Comprehensive Training:** Develop and implement training programs that provide healthcare professionals with a better understanding of autistic needs, including communication and sensory issues. These programs should be widely accessible and include ongoing education.
Recommendation 2	**Policy and Practice Implementation:** Advocate for the consistent implementation of policies that prioritise the needs of autistic individuals across different regions. Address barriers to policy implementation at institutional and systemic levels.
Recommendation 3	**Support Services:** Establish specialised support services that cater to the needs of autistic older adults. These services may include regular check-ins by healthcare professionals, support groups, and tailored interventions to combat isolation.
Recommendation 4	**Sensory-Friendly Healthcare Environments:** Modify healthcare environments to be sensory-friendly, considering lighting, noise levels, and the availability of quiet spaces. Invest in research and development to identify best practices for sensory accommodations.
Recommendation 5	**Improved Communication:** Provide healthcare staff training on effective communication with autistic patients. Promote visual aids, clear language, and

	adapted questioning styles. Encourage healthcare professionals to allocate additional time for appointments.
Recommendation 6	**Continuity of Care:** Ensure continuity of care by assigning the same healthcare professional whenever possible. Ensure that healthcare services communicate effectively with each other to provide seamless care.
Recommendation 7	**Inclusivity in Research:** Encourage research that includes a diverse range of autistic older adults, considering variations in support needs, sensory sensitivities, and cognitive abilities. Explore the long-term impacts of interventions and support services.

4.5 Strengths, limitations, and future directions

This is the first study to qualitatively explore the healthcare experiences of autistic older adults, using semi-structured interviews. A relatively large sample of participants aged 50 years or over from across the UK were recruited through an online survey, which was circulated across a range of different autism-specific networks. This meant that the research team was able to overcome some of the challenges experienced when recruiting autistic older adults who are typically underrepresented in the autism literature (Stuart-Hamilton et al., 2011; Wallace et al., 2016). As such, there was a large enough response rate to purposively sample participants aged 65 years or over from a diverse range of genders and sexual orientations. However, the study struggled to recruit participants from ethnic minority backgrounds, with only one participant from an Asian British background, two from white other backgrounds, and seventeen from white British backgrounds. In addition, previous research has shown that online surveys can introduce selection bias, leading to the recruitment of participants who are more interested in the research topic (Delgado-Rodriguez & Llorca, 2004).

Selection bias can be a significant issue particularly for older age, as circulating the online survey through autism-specific networks might have introduced a 'healthy volunteer' effect where only people who are well connected and more motivated to access healthcare services might have taken part. As such, the research team might not have recruited autistic older adults who are more isolated and less able to access healthcare services. These concerns were somewhat reinforced by the sample characteristics of recruited participants, most of whom were highly educated. With many participants having relatively high levels of

education, a significant proportion were married, and over a quarter were still employed or volunteered. This might suggest that the overall sample interviewed were more healthy and cognitively active than other autistic older adult population (Appendix 13a). However, HM tried to mitigate this issue by collecting information about healthcare status or needs during the online survey (Rubenstein & Furnier, 2021).

In total, there was almost an even split of participants who stated that their current physical or mental health was average or worse. Similarly, whilst some participants stated that they have never had significant physical or mental health difficulties, the vast majority stated that they have had health difficulties and that they have struggled to access services in the past. For a detailed breakdown of physical and mental health characteristics, please see Appendix 13b. Similarly, the research team also made sure that the inclusion criteria for the survey and qualitative interviews were not limited to those with an official autism diagnosis, as autistic older adults are more likely to experience diagnostic barriers (O'Nions et al., 2023). Moreover, HM included people with and without a co-occurring ID to obtain a variety of experiences representative of the broader autism population. However, the interview process may have precluded adults with significant cognitive or language difficulties from participating, and there would have been an issue with capacity to consent as well.

Whilst HM tried to include carers of autistic older adults with a moderate learning disability, only one carer volunteered to take part. Recruiting mainly through an online survey and then asking participants to complete an interview in English might also have been why the research team struggled to recruit autistic older adults from ethnic minority backgrounds. As such, future studies with larger and more diverse samples are required to understand the perspectives of autistic older adults across a range of different identities, including ethnicity, language, race, and support needs. Furthermore, quantitative studies could investigate the healthcare needs of autistic older adults and determine if their experiences affect healthcare service utilisation. Despite this, it is essential to note that qualitative research aims not to

produce generalisable findings but to develop an in-depth understanding of a particular topic or group.

Similarly, and like other methodologies, qualitative research can be influenced by researcher bias. For these reasons, it would have been preferable to include autistic older adults in the research team throughout all study stages. This was not possible due to the constraints of the doctorate. However, the research team did consult with an autistic older adult EbE group during the early stages of the study to ensure that the topic guide questions and study materials were clear and relevant. Some members of the EbE group also helped pilot the online survey and interview topic guide so that they were feasible and acceptable for participants. To minimise researcher bias, HM followed the latest reflexive thematic analysis guidelines and bracketing interviews were conducted between HM and AG to understand better how their positions as outsider researchers might influence the study (Hayfield & Huxley, 2015; Braun & Clarke, 2023). HM and AG also coded each other's first two transcripts, and the wider research team (LO and JS) were consulted in the study's data analysis, theme development, and write-up stages.

4.6 Implications and conclusions

Autistic older adults face a unique set of autism-specific and age-related challenges when accessing healthcare services. While the current findings highlight that they have been struggling with these difficulties their whole lives, the global pandemic and economic situation mean they are at particular risk of being let down. This is very concerning when considering that healthcare services are not designed with autistic people in mind and that they have had to adapt and develop coping strategies to navigate physical, cognitive processing, communication, and sensory difficulties.

While the current study highlights many strengths associated with ageing, it also introduces concerns about the future, when coping strategies and support networks might become more limited. Addressing these challenges requires a multi-faceted approach

encompassing policy changes, healthcare service improvements, and enhanced training for healthcare professionals. By implementing the recommendations outlined above and conducting further research with autistic older adults themselves, services and staff can work towards improving the healthcare experiences of this understudied population. This can also help commissioners design and develop better services that can meet the needs of neurodivergent and ageing populations. Moreover, many recommendations made by participants would help improve outcomes for most people accessing healthcare services in the UK or anywhere.

References

Adams, D., & Young, K. (2020). A systematic review of the perceived barriers and facilitators to accessing psychological treatment for mental health problems in individuals on the autism spectrum. *Review Journal of Autism and Developmental Disorders*, 1-18.

Akobirshoev, I., Mitra, M., Dembo, R., & Lauer, E. (2020). In-hospital mortality among adults with autism spectrum disorder in the United States: A retrospective analysis of US hospital discharge data. *Autism*, *24*(1), 177-189.

Allison, C., Auyeung, B., & Baron-Cohen, S. (2012). Toward brief "red flags" for autism screening: The short autism spectrum quotient and the short quantitative checklist in 1,000 cases and 3,000 controls. *Journal of the American Academy of Child & Adolescent Psychiatry*, *51*(2), 202-212.

American Psychiatric Association. (2022a). Neurodevelopmental Disorders. In Diagnostic and Statistical Manual of Mental Disorders (5th ed., text rev.). https://dsm.psychiatryonline.org/doi/

Atherton, G., Edisbury, E., Piovesan, A., & Cross, L. (2021). Autism through the ages: A mixed methods approach to understanding how age and age of diagnosis affect quality of life. *Journal of Autism and Developmental Disorders*, 1-16.

Autism Act 2009. United Kingdom (2009) https://www.legislation.gov.uk/ukpga/2009/15/contents, Accessed 18th Oct 2021

Baldwin, S., & Costley, D. (2016). The experiences and needs of female adults with high-functioning autism spectrum disorder. *Autism*, *20*(4), 483-495.

Barber, C. (2017). Meeting the healthcare needs of adults on the autism spectrum. *British Journal of Nursing*, *26*(7), 420-425.

Bathelt, J., Koolschijn, P. C., & Geurts, H. M. (2020). Age-variant and age-invariant features of functional brain organization in middle-aged and older autistic adults. *Molecular autism*, *11*(1), 1-14.

Bird, G., & Cook, R. (2013). Mixed emotions: the contribution of alexithymia to the emotional symptoms of autism. *Translational psychiatry*, *3*(7), e285-e285.

Bishop-Fitzpatrick, L., & Kind, A. J. (2017). A scoping review of health disparities in autism spectrum disorder. *Journal of autism and developmental disorders*, *47*, 3380-3391.

Bishop-Fitzpatrick, L., & Rubenstein, E. (2019). The physical and mental health of middle aged and older adults on the autism spectrum and the impact of intellectual disability. *Research in Autism Spectrum Disorders*, *63*, 34-41.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, *3*(2), 77-101.

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative research in sport, exercise and health*, *11*(4), 589-597.

Braun, V., & Clarke, V. (2022). Conceptual and design thinking for thematic analysis. *Qualitative Psychology*, *9*(1), 3.

Braun, V., & Clarke, V. (2023). Toward good practice in thematic analysis: Avoiding common problems and be (com) ing a knowing researcher. *International Journal of Transgender Health*, *24*(1), 1-6.

Brice, S., Rodgers, J., Ingham, B., Mason, D., Wilson, C., Freeston, M., ... & Parr, J. R. (2021). The importance and availability of adjustments to improve access for autistic adults who need mental and physical healthcare: findings from UK surveys. *BMJ open*, *11*(3), e043336.

Brugha, T. S., McManus, S., Bankart, J., Scott, F., Purdon, S., Smith, J., ... & Meltzer, H.

(2011). Epidemiology of autism spectrum disorders in adults in the community in England. *Archives of general psychiatry*, *68*(5), 459-465.

Buckley, C. (2017). Making your practice autism friendly. *InnovAiT*, *10*(6), 327-331.

Calleja, S., Islam, F. M. A., Kingsley, J., & McDonald, R. (2020). Healthcare access for autistic adults: A systematic review. *Medicine*, *99*(29).

Camm-Crosbie, L., Bradley, L., Shaw, R., Baron-Cohen, S., & Cassidy, S. (2019). 'People like me don't get support': Autistic adults' experiences of support and treatment for mental health difficulties, self-injury and suicidality. *Autism*, *23*(6), 1431-1441.

Cederlund, M., Hagberg, B., Billstedt, E., Gillberg, I. C., & Gillberg, C. (2008). Asperger syndrome and autism: A comparative longitudinal follow-up study more than 5 years after original diagnosis. *Journal of autism and developmental disorders*, *38*, 72-85.

Clarke, V., & Braun, V. (2013). Successful qualitative research: A practical guide for beginners. *Successful qualitative research*, 1-400.

Crane, L., Batty, R., Adeyinka, H., Goddard, L., Henry, L. A., & Hill, E. L. (2018). Autism diagnosis in the United Kingdom: Perspectives of autistic adults, parents and professionals. *Journal of autism and developmental disorders*, *48*, 3761-3772.

Creswell, J. W., & Poth, C. N. (2016). *Qualitative inquiry and research design: Choosing among five approaches*. Sage publications.

Croen, L. A., Zerbo, O., Qian, Y., Massolo, M. L., Rich, S., Sidney, S., & Kripke, C. (2015). The health status of adults on the autism spectrum. *Autism*, *19*(7), 814-823.

Cummins, C., Pellicano, E., & Crane, L. (2020). Autistic adults' views of their communication skills and needs. *International journal of language & communication disorders*, *55*(5), 678-689.

Delgado-Rodriguez, M., & Llorca, J. (2004). Bias. *Journal of Epidemiology & Community Health*, *58*(8), 635-641.

Doherty, A. J., Atherton, H., Boland, P., Hastings, R., Hives, L., Hood, K., ... & Chauhan, U. (2020). Barriers and facilitators to primary health care for people with intellectual disabilities and/or autism: an integrative review. *BJGP open*, *4*(3).

Doherty, M., Haydon, C., & Davidson, I. A. (2021). Recognising autism in healthcare. *British Journal of Hospital Medicine*, *82*(12), 1-7.

Doherty, M., Neilson, S., O'Sullivan, J., Carravallah, L., Johnson, M., Cullen, W., & Shaw, S. C. (2022). Barriers to healthcare and self-reported adverse outcomes for autistic adults: a cross-sectional study. *BMJ open*, *12*(2), e056904.

Etgeton, S., Fischer, B., & Ye, H. (2023). The effect of increasing retirement age on households' savings and consumption expenditure. *Journal of Public Economics*, *221*, 104845.

Fossey, E., Harvey, C., McDermott, F., & Davidson, L. (2002). Understanding and evaluating qualitative research. *Australian & New Zealand journal of psychiatry*, *36*(6), 717-732.

Foster, S. (2022). New mandatory training set to transform outcomes for clients with learning disability. *British Journal of Nursing*, *31*(19), 1011-1011.

Geurts, H. M., & Vissers, M. E. (2012). Elderly with autism: Executive functions and memory. *Journal of autism and developmental disorders*, *42*, 665-675.

Geurts, H. M., Charlton, R., & Bishop, L. (2021). Ageing when being autistic. In *Handbook on ageing with disability* (pp. 148-158). Routledge.

Gotham, K., Brunwasser, S. M., & Lord, C. (2015). Depressive and anxiety symptom trajectories from school age through young adulthood in samples with autism spectrum disorder and developmental delay. *Journal of the American Academy of Child & Adolescent Psychiatry*, *54*(5), 369-376.

Griffith, G. M., Totsika, V., Nash, S., & Hastings, R. P. (2012). 'I just don't fit anywhere': support experiences and future support needs of individuals with Asperger syndrome in middle adulthood. *Autism*, *16*(5), 532-546.

Hand, B. N., Angell, A. M., Harris, L., & Carpenter, L. A. (2020). Prevalence of physical and mental health conditions in Medicare-enrolled, autistic older adults. *Autism*, *24*(3), 755-764.

Happé, F. G., Mansour, H., Barrett, P., Brown, T., Abbott, P., & Charlton, R. A. (2016). Demographic and cognitive profile of individuals seeking a diagnosis of autism

spectrum disorder in adulthood. *Journal of Autism and Developmental Disorders*, *46*, 3469-3480.

Happé, F., & Charlton, R. (2012). Mini review: Aging in autism spectrum disorders.

Happé, F., & Frith, U. (2020). Annual Research Review: Looking back to look forward–changes in the concept of autism and implications for future research. *Journal of Child Psychology and Psychiatry*, *61*(3), 218-232.

Harvery, M., Froude, E. H., Foley, K. R., Trollor, J. N., & Arnold, S. R. (2021). Employment profiles of autistic adults in Australia. *Autism Research*, *14*(10), 2061-2077.

Hayfield, N., & Huxley, C. (2015). Insider and outsider perspectives: Reflections on researcher identities in research with lesbian and bisexual women. *Qualitative research in psychology*, *12*(2), 91-106.

Hennink, M., & Kaiser, B. N. (2022). Sample sizes for saturation in qualitative research: A systematic review of empirical tests. *Social science & medicine*, *292*, 114523.

Hickey, A., Crabtree, J., & Stott, J. (2018). 'Suddenly the first fifty years of my life made sense': Experiences of older people with autism. *Autism*, *22*(3), 357-367.

Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P., & Bölte, S. (2016). Premature mortality in autism spectrum disorder. *The British Journal of Psychiatry*, *208*(3), 232-238.

Howlin, P., Goode, S., Hutton, J., & Rutter, M. (2004). Adult outcome for children with autism. *Journal of child psychology and psychiatry*, *45*(2), 212-229.

Huang, Y., Arnold, S. R., Foley, K. R., & Trollor, J. N. (2020). Diagnosis of autism in adulthood: A scoping review. *Autism*, *24*(6), 1311-1327.

Huang, Y., Arnold, S. R., Foley, K. R., Lawson, L. P., Richdale, A. L., & Trollor, J. N. (2021). Factors associated with age at autism diagnosis in a community sample of Australian adults. *Autism Research*, *14*(12), 2677-2687.

Jadav, N., & Bal, V. H. (2022). Associations between co-occurring conditions and age of autism diagnosis: Implications for mental health training and adult autism research. *Autism Research*, *15*(11), 2112-2125.

Jones, L., Goddard, L., Hill, E. L., Henry, L. A., & Crane, L. (2014). Experiences of receiving a diagnosis of autism spectrum disorder: A survey of adults in the United Kingdom. *Journal of autism and developmental disorders*, *44*, 3033-3044.

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, *20*(4), 442-462.

Kinnear, D., Rydzewska, E., Dunn, K., Hughes-McCormack, L., Melville, C., Henderson, A., & Cooper, S. A. (2020). The relative influence of intellectual disabilities and autism on sensory impairments and physical disability: A whole-country cohort of 5.3 million children and adults. *Journal of Applied Research in Intellectual Disabilities*, *33*(5), 1059-1068.

Lai, M. C., & Baron-Cohen, S. (2015). Identifying the lost generation of adults with autism spectrum conditions. *The Lancet Psychiatry*, *2*(11), 1013-1027.

Leedham, A., Thompson, A. R., Smith, R., & Freeth, M. (2020). 'I was exhausted trying to figure it out': The experiences of females receiving an autism diagnosis in middle to late adulthood. *Autism*, *24*(1), 135-146.

Lehnhardt, F. G., Gawronski, A., Pfeiffer, K., Kockler, H., Schilbach, L., & Vogeley, K. (2013). The investigation and differential diagnosis of Asperger syndrome in adults. *Deutsches Ärzteblatt International*, *110*(45), 755.

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

Lewis, L. F. (2016). Realizing a diagnosis of autism spectrum disorder as an adult. *International journal of mental health nursing*, *25*(4), 346-354.

Lipinski, S., Blanke, E. S., Suenkel, U., & Dziobek, I. (2019). Outpatient psychotherapy for adults with high-functioning autism spectrum condition: utilization, treatment satisfaction, and preferred modifications. *Journal of autism and developmental disorders*, *49*, 1154-1168.

Livingston, L. A., & Happé, F. (2017). Conceptualising compensation in neurodevelopmental disorders: Reflections from autism spectrum disorder. *Neuroscience & Biobehavioral Reviews*, *80*, 729-742.

Lord, C., Charman, T., Havdahl, A., Carbone, P., Anagnostou, E., Boyd, B., ... & McCauley, J. B. (2022). The Lancet Commission on the future of care and clinical research in autism. *The Lancet*, *399*(10321), 271-334.

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

Malterud, K., Siersma, V. D., & Guassora, A. D. (2016). Sample size in qualitative interview studies: guided by information power. *Qualitative health research*, *26*(13), 1753-1760.

Mason, D., Ingham, B., Urbanowicz, A., Michael, C., Birtles, H., Woodbury-Smith, M., ... & Parr, J. R. (2019). A systematic review of what barriers and facilitators prevent and enable physical healthcare services access for autistic adults. *Journal of autism and developmental disorders*, *49*, 3387-3400.

Mason, D., Stewart, G. R., Capp, S. J., & Happé, F. (2022). Older age autism research: A rapidly growing field, but still a long way to go. *Autism in Adulthood*, *4*(2), 164-172.

Mazurek, M. O., Sadikova, E., Cheak-Zamora, N., Hardin, A., Sohl, K., & Malow, B. A. (2023). Health Care Needs, Experiences, and Perspectives of Autistic Adults. *Autism in Adulthood*, *5*(1), 51-62.

McKee, M., Dunnell, K., Anderson, M., Brayne, C., Charlesworth, A., Johnston-Webber, C., ... & Watt, R. G. (2021). The changing health needs of the UK population. *The Lancet*, *397*(10288), 1979-1991.

Morgan, E., & Rozée, S. (2020). National life tables–life expectancy in the UK: 2017 to 2019. *Office of National Statistics.[Google Scholar]*.

NHS. The NHS long term plan. 2019. https://www.longtermplan.nhs.uk/

Nicolaidis, C., Raymaker, D. M., Ashkenazy, E., McDonald, K. E., Dern, S., Baggs, A. E., ...

& Boisclair, W. C. (2015). “Respect the way I need to communicate with you”: Healthcare experiences of adults on the autism spectrum. *Autism*, *19*(7), 824-831.

Nicolaidis, C., Raymaker, D., Kapp, S. K., Baggs, A., Ashkenazy, E., McDonald, K., ... & Joyce, A. (2019). The AASPIRE practice-based guidelines for the inclusion of autistic adults in research as co-researchers and study participants. *Autism*, *23*(8), 2007-2019.

Nicolaidis, C., Raymaker, D., McDonald, K., Dern, S., Boisclair, W. C., Ashkenazy, E., & Baggs, A. (2013). Comparison of healthcare experiences in autistic and non-autistic adults: a cross-sectional online survey facilitated by an academic-community partnership. *Journal of general internal medicine*, *28*, 761-769.

Oberman, L. M., Rotenberg, A., & Pascual-Leone, A. (2014). Aberrant brain plasticity in autism spectrum disorders. *Cognitive plasticity in neurologic disorders*, 176-196.

O'Nions, E., Petersen, I., Buckman, J. E., Charlton, R., Cooper, C., Corbett, A., ... & Stott, J. (2023). Autism in England: assessing underdiagnosis in a population-based cohort study of prospectively collected primary care data. *The Lancet Regional Health–Europe*, *29*.

Pearson, A., Rose, K., & Rees, J. (2023). ‘I felt like I deserved it because I was autistic’: Understanding the impact of interpersonal victimisation in the lives of autistic people. *Autism*, *27*(2), 500-511.

Pelikan, J. M., Ganahl, K., Van den Broucke, S., & Sørensen, K. (2019). Measuring health literacy in Europe: introducing the European health literacy survey questionnaire (HLS-EU-Q). In *International handbook of health literacy* (pp. 115-138). Policy Press.

Pham, A. V., & Charles, L. C. (2023). Racial Disparities in Autism Diagnosis, Assessment, and Intervention among Minoritized Youth: Sociocultural Issues, Factors, and Context. *Current Psychiatry Reports*, *25*(5), 201-211.

Pilling, S., Baron-Cohen, S., Megnin-Viggars, O., Lee, R., & Taylor, C. (2012). Recognition, referral, diagnosis, and management of adults with autism: summary of NICE guidance. *Bmj*, *344*.

Powell, T., & Acker, L. (2016). Adults' experience of an Asperger syndrome diagnosis: Analysis of its emotional meaning and effect on participants' lives. *Focus on Autism and Other Developmental Disabilities*, *31*(1), 72-80.

Ratto, A. B., Bascom, J., daVanport, S., Strang, J. F., Anthony, L. G., Verbalis, A., ... & Kenworthy, L. (2023). Centering the Inner Experience of Autism: Development of the Self-Assessment of Autistic Traits. *Autism in Adulthood*, *5*(1), 93-105.

Robison, J. E. (2019). Talking about autism—thoughts for researchers. *Autism Research*, *12*(7), 1004-1006.

Roestorf, A., Bowler, D. M., Deserno, M. K., Howlin, P., Klinger, L., McConachie, H., ... & Geurts, H. M. (2019). "Older Adults with ASD: The Consequences of Aging." Insights from a series of special interest group meetings held at the International Society for Autism Research 2016–2017. *Research in Autism Spectrum Disorders*, *63*, 3-12.

Rose, L. (2020). Retirement and health: Evidence from England. *Journal of Health Economics*, *73*, 102352.

Roulston, K. (2010). Reflective interviewing: A guide to theory and practice. *Reflective Interviewing*, 1-216.

Royal College of Psychiatrists. (2020). The psychiatric management of autism in adults (CR228). RCP.

Rubenstein, E., & Furnier, S. (2021). # Bias: The opportunities and challenges of surveys that recruit and collect data of autistic adults online. *Autism in Adulthood*, *3*(2), 120-128.

Russell, G., Stapley, S., Newlove-Delgado, T., Salmon, A., White, R., Warren, F., ... & Ford, T. (2022). Time trends in autism diagnosis over 20 years: a UK population-based cohort study. *Journal of Child Psychology and Psychiatry*, *63*(6), 674-682.

Rutter, M. (2005). Incidence of autism spectrum disorders: changes over time and their meaning. *Acta paediatrica*, *94*(1), 2-15.

Rydzewska, E., Hughes-McCormack, L. A., Gillberg, C., Henderson, A., MacIntyre, C., Rintoul, J., & Cooper, S. A. (2019). General health of adults with autism spectrum

disorders–a whole country population cross-sectional study. Research in Autism Spectrum Disorders, 60, 59-66.

Sangha, O., Stucki, G., Liang, M. H., Fossel, A. H., & Katz, J. N. (2003). The Self-Administered Comorbidity Questionnaire: a new method to assess comorbidity for clinical and health services research. *Arthritis Care & Research: Official Journal of the American College of Rheumatology*, *49*(2), 156-163.

Scott, M., & Rawal, S. (2018). The promise of equity: a review of health equity research in high-impact quality improvement journals. *American Journal of Medical Quality*, *33*(3), 269-273.

Slater, M., Abelson, J., Wong, S. T., Langton, J. M., Burge, F., Hogg, W., ... & Johnston, S. (2020). Priority measures for publicly reporting primary care performance: Results of public engagement through deliberative dialogues in 3 Canadian provinces. *Health Expectations*, *23*(5), 1213-1223.

Sonido, M., Arnold, S., Higgins, J., & Hwang, Y. I. J. (2020). Autism in later life: What is known and what is needed?. *Current Developmental Disorders Reports*, *7*, 69-77.

Stuart-Hamilton, I., & Morgan, H. (2011). What happens to people with autism spectrum disorders in middle age and beyond? Report of a preliminary on-line study. *Advances in Mental Health and Intellectual Disabilities*, *5*(2), 22-28.

Underwood, J. F., DelPozo-Banos, M., Frizzati, A., Rai, D., John, A., & Hall, J. (2023). Neurological and psychiatric disorders among autistic adults: a population healthcare record study. *Psychological Medicine*, *53*(12), 5663-5673.

Unigwe, S., Buckley, C., Crane, L., Kenny, L., Remington, A., & Pellicano, E. (2017). GPs' confidence in caring for their patients on the autism spectrum: an online self-report study. *British Journal of General Practice*, *67*(659), e445-e452.

United Nations. (2019). United Nations word population prospects 2020. Retrieved November 29, 2019 from https://population.un.org/wpp/DataQuery

Vogan, V., Lake, J. K., Tint, A., Weiss, J. A., & Lunsky, Y. (2017). Tracking health care service use and the experiences of adults with autism spectrum disorder without

intellectual disability: A longitudinal study of service rates, barriers and satisfaction. *Disability and Health Journal*, *10*(2), 264-270.

Vohra, R., Madhavan, S., & Sambamoorthi, U. (2016). Emergency department use among adults with autism spectrum disorders (ASD). *Journal of autism and developmental disorders*, *46*, 1441-1454.

Wallace, G. L., Budgett, J., & Charlton, R. A. (2016). Aging and autism spectrum disorder: Evidence from the broad autism phenotype. *Autism Research*, *9*(12), 1294-1303.

Walsh, C., Lydon, S., O'Dowd, E., & O'Connor, P. (2020). Barriers to healthcare for persons with autism: a systematic review of the literature and development of a taxonomy. *Developmental Neurorehabilitation*, *23*(7), 413-430.

Walsh, N., & Hall, I. (2012). The Autism Strategy: implications for people with autism and for service development. *Advances in Mental Health and Intellectual Disabilities*, *6*(3), 113-120.

Whitehead, M., & Dahlgren, G. (1991). What can be done about inequalities in health?. *The lancet*, *338*(8774), 1059-1063.

World Health Organization. (2013). Meeting report: autism spectrum disorders and other developmental disorders: from raising awareness to building capacity: World Health Organization, Geneva, Switzerland 16-18 September 2013.

World Health Organization. (2015). *World report on ageing and health*. World Health Organization.

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and health*, *15*(2), 215-228.

Yardley, L. (2017). Demonstrating the validity of qualitative research. *The journal of positive psychology*, *12*(3), 295-296.

Part 3: Critical Appraisal

In this section, I provide a critical appraisal of the processes involved in completing this thesis. I will also reflect on how my decisions might have affected the outcomes of the systematic review and empirical paper. First, I will explain why I chose to investigate this topic and how I selected meta-analysis and reflexive thematic analysis as the primary research methods for both projects, respectively. Then, I will discuss the challenges I encountered while designing and carrying out the systematic review both conceptually and methodologically. Next, I will describe the different stages of the empirical paper and emphasise the importance of self-awareness in understanding how my position as an outsider researcher may have influenced data collection, data analysis, and the write-up. Finally, I will analyse how the findings from both projects can contribute to clinical practice and research, specifically in enhancing our understanding of the healthcare needs and experiences of autistic populations.

Reasons for choosing this topic

Initially, I was drawn to this topic because it allowed me to pursue multiple passions and enhance my research skills. My past experiences of working in an autism diagnostic centre gave me some insights into the lack of post-diagnostic support available for autistic individuals and their families. Similarly, working as a research assistant on a randomised control trial for neurotypical older adults with mild cognitive impairments sparked my interest in older adult research. Therefore, this project was the perfect opportunity to combine both interests in ageing and autism research. The overall goals of the topic also aligned with the methodological approaches I wanted to learn and develop.

Although I had previous experience conducting qualitative interviews with older adults, I wanted to gain further experience with reflexive thematic analysis because I have always felt more comfortable using quantitative methodologies. Similarly, while I was previously involved in a systematic review, I had never completed a meta-analysis or led a review from inception to completion. As such, when I saw this topic advertised within the DClinPsy project catalogue, I felt that it was a good opportunity to develop as a researcher and contribute to the literature. However, I feel as though my previous experiences made me overly ambitious, which meant

that I took on more than was necessary, especially considering the competing demands of the doctorate, clinical placement, and general life.

Importance of collaborative working

For this reason, working on the project alongside AG, with LO and JS as our supervisors, was very helpful. LO and JS provided us with the necessary support and guidance while allowing us the freedom to work independently and shape the project according to our own interests. By collaborating on the empirical project, AG and I were able to split tasks according to our individual strengths. For example, AG created posters, consent forms, and participant information sheets, while I took care of finding the online survey questionnaires, completed the power calculation, and amended the ethical approval form after AG had submitted. In addition, collaborating with a patient and public involvement group consisting of autistic older adult experts-by-experience (EbE) was an invaluable experience that allowed us to co-produce resources and pilot the online survey. Although we could not involve the EbE group in the later stages of the study due to time constraints, we plan to speak with them once we have finalised our findings.

Finding a systematic review question

During my search for a systematic review topic related to the healthcare experiences of autistic older adults, I encountered some difficulties due to the COVID-19 pandemic. As such, many systematic reviews on similar topics had already been published or were registered on PROSPERO for future publication. However, I came across some studies that examined trauma and posttraumatic symptomology in individuals with high autistic traits or who self-identified as being autistic. These studies found that people in the probable autism group were more likely to experience traumatic events throughout their lives and displayed increased symptoms that met the clinical cut-off for posttraumatic stress disorder (PTSD), compared to neurotypical controls (Stewart et al., 2022; Haruvi-Lamdan et al., 2020; Rumball et al., 2021). Despite consistent findings and several reviews discussing the link between autism and PTSD,

no study had explored the prevalence rates of PTSD in autism (Haruvi-Lamdan et al., 2018; Peterson et al., 2019; Kildahl et al., 2019).

While one review did investigate the assessment and treatment of PTSD in autistic populations, it only included a small table that reported the mean PTSD prevalence rates for child-adolescent and adult studies (Rumball, 2019). Moreover, the search was conducted in 2016, and the review did not conduct a meta-analysis to look at PTSD prevalence rates. This meant that there were only a limited number of studies in each category, particularly in the adult study category, which only had two studies included. Furthermore, the review did not investigate the influence of sample characteristics on prevalence rates. This is particularly important as factors such as gender, ethnicity, and level of cognitive function have all been found to affect PTSD diagnostic rates in neurotypical populations (Shalev et al., 2019; Alegría et al., 2013; Daveney et al., 2019). Therefore, it was appropriate to review the prevalence rates of PTSD in autism and tentatively explore whether sample characteristics influenced the pooled prevalence rate.

Systematic review search strategy

In accordance with the PRISMA guidelines, I created and registered a detailed protocol with PROSPERO (Registration Number: CRD42022350068) for my systematic review question. To ensure a comprehensive search strategy, I looked for other meta-analysis studies that investigated the co-occurrence of general mental health difficulties and more specific mental health conditions, such as psychosis or bipolar, with autism (Lai et al., 2019; Varcin et al., 2022). I noticed that the term "psychiatric comorbidity" was frequently used in their searches. Therefore, I added "psychiatric comorbid*" to my search terms, which helped me identify nearly 4,000 additional articles. Although this was a significant number, I used Rayyan, an open-source review management software, to screen and select the papers based on pre-specified inclusion criteria (Ouzzani et al., 2016).

Moreover, I had the valuable assistance of two friends who helped me double-screen the identified studies. During the title and abstract stage, IA screened 10% of all studies, while SK screened all studies during the full-text screening stage. We were inclusive during the title and abstract screening stage, as some studies might report PTSD prevalence rates in the text or results section but not in the abstract or title. SK also helped me with the data extraction and risk of bias assessment stages of the review. Having a second coder to compare results with was incredibly helpful, and SK had prior experience using the Newcastle Ottawa scale (Wells et al., 2000; Herzog et al., 2013). This meant that she could advise me on how best to adapt the scale for cross-sectional studies, which she also used in another review she was conducting as part of her role as a research assistant at University College London (UCL).

Systematic review methodological choices

Before registering the review on PROSPERO, it was crucial to determine the primary focus of the review. Investigating all studies that have explored PTSD prevalence rates and symptomology in autistic populations would have been too broad and repetitive, considering the amount of past research on the subject. Moreover, no 'gold standard' prevalence rate for PTSD within autism could be found in the literature. Therefore, we decided to concentrate the review on the recorded prevalence rates of PTSD within diagnosed autistic populations, ensuring the specificity of our results to autism. To achieve this, we only included studies that used reliable diagnostic criteria for autism and PTSD.

However, this approach may have limited the generalisability of our findings as many autistic individuals, especially in adulthood, do not have an official autism diagnosis (O'Nions et al., 2023). Despite this limitation, the review focus allowed us to investigate whether the recorded PTSD prevalence rates reflect the increased PTSD symptoms observed in probable autism populations, which can provide recommendations for clinical practice and future research. Additionally, to ensure the accuracy of our results, we only included studies that used stringent diagnostic criteria and assessment methods for PTSD. Again, this might have underestimated the actual PTSD prevalence rates as many autistic individuals might not

receive an official diagnosis, even though their posttraumatic symptoms meet the clinical cut-off. Nevertheless, understanding the most accurate recorded prevalence rates of PTSD among autistic populations is essential as many healthcare services rely on these diagnostic criteria to provide support.

Conducting the meta-analysis

Initially, I had some doubts about conducting a meta-analysis due to the high levels of heterogeneity between some studies. However, after discussion with some post-doctoral researchers (RD, AJ, and CEB) at UCL I found out that this is a common issue faced by many prevalence-based reviews. As a result, I was able to use a random-effects model to control for high to moderate heterogeneity (Bell et al., 2019). In addition, I also conducted outlier and publication bias analyses, calculating separate prevalence rates without outlier studies (Egger et al., 1997). Furthermore, I used subgroup analyses to investigate the impact of sample characteristics on overall pooled prevalence rates. Although I was unable to conduct a meta-regression due to inconsistencies between sample characteristic information, I was able to use a median split method to investigate the influence of proportion gender and ethnicity. Similarly, I due to lack of consistent information about the number of participants in each sample with a co-occurring intellectual disability I split studies into those which did and did not include intellectual disability into their sample.

However, it is important to note that these subgroup analyses are exploratory, and further research is needed. Similarly, although the aim of the review was to produce the most accurate “gold standard” recorded prevalence of PTSD within autism. The analysis became more complicated as the review progressed. For instance, it became clear that I needed to conduct a separate meta-analysis for child-adolescent and adult studies. This also had to be done for current and lifetime PTSD prevalence rates, which then affected the number of subgroup analyses I had to complete for different sample characteristics. All these extra levels made the analysis much more extensive and time-consuming than I had originally planned. However, it also made the overall findings and conclusions more worthwhile. Moreover, I

gained valuable experience in conducting a meta-analysis and learned how to use R, a data analysis program that I had not previously used.

Designing the empirical paper

The handbook initially advertised a study about the healthcare experiences of autistic adults aged 50 years or over. However, our supervisors allowed us to customise the project according to our strengths and interests. Although I had some concerns about recruiting enough older adults for the semi-structured interviews, we decided to add an online survey to aid in recruiting interested participants and characterising the overall sample. Whilst creating the online survey took a lot of extra time and effort, it made me feel more comfortable about the project as I have more experience using quantitative and mixed methods approaches. Having AG as a research partner was also very helpful as we could share the tasks and create a survey that would help us both recruit for our studies which had separate interests.

Initially, AG was aiming to investigate the healthcare experience of autistic adults with co-occurring intellectual disabilities or their carers, while I would focus on autistic adults without co-occurring intellectual disabilities. However, due to difficulties in recruiting enough carers, AG shifted her focus to investigate the healthcare experience of autistic women aged 50 or over, while I focused on investigating the healthcare experiences of autistic older adults aged 65 years or over, regardless of whether they have a co-occurring intellectual disability or not. Although this change in research focus felt very anxiety-provoking, we both quickly realised that the extra effort we had placed in creating the online survey and infographic posters was worthwhile.

Recruiting for the online survey

We promoted our studies through various organisations, including the National Autistic Society, Mencap, and Pathway Associates (a not-for-profit organisation). However, the response rates were initially very low, especially in the first month. Therefore, we started to email more local organisations throughout the UK and specific charities that focused on autism

and intellectual disabilities. The key breakthrough came when Autistica decided to circulate our survey through their mailing list, and within a few weeks of their email being sent, we received more than 100 responses. This was very reassuring, as it showed that there was a high demand for research in this area. Most respondents completed the entire survey, even though it was relatively lengthy and included general demographic questions, an autism quotient questionnaire, a health literacy questionnaire, physical and mental health comorbidity questionnaires, and open-ended response questions about healthcare experiences (Allison et al., 2011; Pelikan et al., 2019; Sangha et al., 2003). We were concerned that some of the responses might be fake, but we were able to screen them out by looking at the open-ended question responses, completion rates/times, and by checking the respondents' IP addresses through Qualtrics.

In total, we had 188 individuals who completed the online survey, with 133 expressing an interest in participating in qualitative interviews. One of the main reasons the online survey was so successful was because of the input and feedback we received from the EbE group. They did an incredible job in helping us check all the resources and pilot the survey so that it was feasible and acceptable for individuals to complete. Their recommendations led to us adding a completion bar to the top of the survey, so participants knew how many more sections they still had to complete. We also designed the survey so that people could come back to complete their responses without losing all their progress. Moreover, by asking some members of the EbE group to pilot the survey and our topic guide, we became more confident that we had included the right questions and were focusing on the relevant topics. This was also the feedback I received from participants who took part in the interviews.

Recruiting for the interviews

When recruiting for the qualitative interviews, it was difficult to determine whether we had introduced selection bias into our final pool of participants. This was because there was no way for us to check where we had recruited all our online survey participants from, and it was highly likely that most of them were from Autistica because we had such a high surge a few

weeks after advertising through their mailing list. As such, whilst the online survey allowed us to conveniently sample participants interested in taking part in our study, it also might have meant that we only obtained individuals who had access to the internet and those who might be well-connected with autism organisations such as Autistica (Eysenbach & Wyatt, 2002). This is particularly important when thinking about older adult populations where more active and potentially healthier participants are more likely to complete the survey and register their interest for the interviews. However, we tried to mitigate for this issue by collecting general demographic, healthcare needs, and service utilisation information during the survey (Rubenstein & Furnier, 2021). Moreover, it is important to note that the issue of selection bias is not just limited to online surveys or our study.

In fact, by advertising our study through the National Autistic Society and Autistica, we were able to reach out to an extensive network of different autistic-specific organisations across the UK. Similarly, by also including those who self-identify as being autistic, we increased the overall generalisability of our sample as many autistic adults do not have an official autism diagnosis, particularly in older age (O'Nions et al., 2023). This might be one of the reasons we were able to recruit autistic adults aged from 50 to 75, who were from a wide range of different sociodemographic backgrounds. However, despite concerted efforts to advertise through specialist networks such as @BlackAutistics on Twitter, we were not able to increase the level of ethnic diversity within our sample. This was something which might have been improved if I had more time and resources to recruit directly from the community. However, despite these shortcomings, I was still able to recruit 20 autistic older adults aged 65 years or over to take part in the interview and purposively sample for underrepresented characteristics such as older age, gender, and different sexual orientations.

Interviews and data analysis

During the interview process, I intentionally recruited participants with varying autism diagnoses and intellectual disabilities statuses to ensure a diverse range of experiences and perspectives were represented in the data. However, my outsider position as a non-autistic

researcher meant that there were times when I became overly anxious about saying or doing the wrong thing. This anxiety was particularly strong during the early stages of the interviews and during the data analysis stages of the study. As such, during the interviews, there were times when I struggled to interrupt participants or to ask them to focus specifically on the questions. This was one of the main reasons why some interviews overran, but it also meant that participants felt more comfortable sharing their experiences. Similarly, when coding and writing up the results, I became extremely anxious about whether my themes were too broad and if they truly captured the participants' experiences. I also felt the need to find the perfect quotes for each theme and do justice to each participant's stories. At this moment, it was extremely helpful to have LO and JS as my supervisors as they were able to provide me with guidance and support to not overthink things.

Importance of being reflexive

It was also very helpful to conduct a bracketing interview with AG and to keep a journal during the interviews. This helped me become a more reflexive researcher as I was required to think about how my previous life experiences, assumptions, values, and theoretical preferences might have influenced the research (Berger, 2015; McLeod, 2011). It was particularly helpful to think about how my past experiences as a psychologist, research assistant, and carer influenced the way I viewed healthcare services, autism, and ageing. During the bracketing interviews, I noticed that all my previous research and clinical experiences were associated with the medical model of disability. Similarly, I assumed that ageing and autism would be associated with increased difficulties. By acknowledging these assumptions, I was able to approach the interviews with a more open mindset where I would ask about both strengths and difficulties. However, it is important to note that reflexivity does not 'eliminate' bias, but it helps the researcher to think about how meaning is co-constructed (Braun & Clarke, 2006).

Being reflexive also helped me when I encountered feelings of frustration and helplessness towards participants' experiences and the current state of the healthcare system. Nearly all participants spoke about the lack of mental health and social care support within the

UK and how healthcare services are becoming less accessible during times of austerity. Some of these experiences were difficult to sit with and there were times when I would struggle to maintain a neutral 'researcher stance'. However, by speaking with friends and some of the research team I was able to understand how these feelings might also have been associated with my own experiences of accessing healthcare services for my family. Similarly, it was also helpful to create spaces within the interview where participants were invited to speak about any strengths, resources, and support networks. This led to a feeling of hope and inspiration, but I feel as though I should have been more comfortable asking about difficult topics. For example, it wasn't until the last few interviews that I noticed that I did not have a single question about the future. Although many participants shared concerns about age-related cognitive or physical decline and the possibility of having to go into a care home, I feel like I could have asked more about these concerns. In fact, upon listening back to some of the other interviews, I noticed that I did not pick up on subtle cues about similar topics.

Impact of the current study

Whilst I initially had concerns about completing a purely qualitative empirical paper, I quickly realised that I had more than enough data without also including survey responses. During this time, it was extremely helpful to have JS and LO as my supervisors because they were able to help me manage my expectations and scale back the empirical paper. By focusing only on the semi-structured interviews, I had more time and space to concentrate on participants' experiences using their own words. This approach paid off when I presented the study's qualitative findings at an ageing and autism conference, where one attendee remarked that some of the quotes and findings were very neuro-affirmative. It also meant that the final write-up was a lot more specific and focussed on autistic older adult's experiences of accessing healthcare services in the UK.

Personally, I also learned a lot from speaking with participants, and both projects have influenced my clinical work. For example, the systematic review exposed some of the limitations of using stringent diagnostic criteria, which may have been developed with

neurotypical populations in mind. Similarly, the subgroup analysis highlighted the impact of certain factors on prevalence rates and the importance of including multiple sources of information during the assessment. As for the empirical, I am now more comfortable asking people about their preferences and better able to adapt my approach to their strengths and needs. This is especially important in becoming a more collaborative and person-centred practitioner. I also hope to publish both studies in peer-reviewed journals and to continue disseminating findings across different organisations and healthcare services.

References

Alegría, M., Fortuna, L. R., Lin, J. Y., Norris, F. H., Gao, S., Takeuchi, D. T., Jackson, J. S., Shrout, P. E., & Valentine, A. (2013). Prevalence, Risk, and Correlates of Posttraumatic Stress Disorder Across Ethnic and Racial Minority Groups in the United States. *Medical Care*, *51*(12), 1114–1123. https://doi.org/10.1097/mlr.0000000000000007

Allison, C., Auyeung, B., & Baron-Cohen, S. (2012). Toward brief "red flags" for autism screening: The short autism spectrum quotient and the short quantitative checklist in 1,000 cases and 3,000 controls. *Journal of the American Academy of Child & Adolescent Psychiatry*, *51*(2), 202-212.

Bell, A., Fairbrother, M., & Jones, K. (2019). Fixed and random effects models: making an informed choice. Quality & quantity, 53, 1051-1074.

Berger, R. (2015). Now I see it, now I don't: Researcher's position and reflexivity in qualitative research. *Qualitative research*, *15*(2), 219-234.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, *3*(2), 77-101.

Daveney, J., Hassiotis, A., Katona, C., Matcham, F., & Sen, P. (2019). Ascertainment and Prevalence of Post-Traumatic Stress Disorder (PTSD) in People with Intellectual Disabilities. *Journal of Mental Health Research in Intellectual Disabilities*, *12*(3-4), pp. 211–233. https://doi.org/10.1080/19315864.2019.1637979

Egger, M., Smith, G. D., Schneider, M., & Minder, C. (1997). Bias in meta-analysis detected by a simple, graphical test. *BMJ*, *315*(7109), 629–634. https://doi.org/10.1136/bmj.315.7109.629

Eysenbach, G., & Wyatt, J. (2002). Using the Internet for surveys and health research. Journal of medical Internet research, 4(2), e862.

Haruvi-Lamdan, N., Horesh, D., & Golan, O. (2018). PTSD and autism spectrum disorder: Co-morbidity, gaps in research, and potential shared mechanisms. *Psychological Trauma: Theory, Research, Practice, and Policy*, *10*(3), 290–299. https://doi.org/10.1037/tra0000298

Haruvi-Lamdan, N., Horesh, D., Zohar, S., Kraus, M., & Golan, O. (2020). Autism Spectrum Disorder and Post-Traumatic Stress Disorder: An unexplored co-occurrence of conditions. *Autism*, *24*(4), 884–898. https://doi.org/10.1177/1362361320912143

Herzog, R., Álvarez-Pasquin, M., Díaz, C., Del Barrio, J. L., Estrada, J. M., & Gil, Á. (2013). Are healthcare workers' intentions to vaccinate related to their knowledge, beliefs and attitudes? A systematic review. BMC public health, 13(1), 1-17.

Kildahl, A. N., Bakken, T. L., Iversen, T. E., & Helverschou, S. B. (2019). Identification of Post-Traumatic Stress Disorder in Individuals with Autism Spectrum Disorder and Intellectual Disability: A Systematic Review. *Journal of Mental Health Research in Intellectual Disabilities*, *12*(1-2), 1–25. https://doi.org/10.1080/19315864.2019.1595233

Lai, M.-C., Kassee, C., Besney, R., Bonato, S., Hull, L., Mandy, W., Szatmari, P., & Ameis, S. H. (2019). Prevalence of co-occurring mental health diagnoses in the autism population: a systematic review and meta-analysis. *The Lancet Psychiatry*, *6*(10), 819–829. https://doi.org/10.1016/s2215-0366(19)30289-5

McLeod, J. (2011). Qualitative research in counselling and psychotherapy. Qualitative research in counselling and psychotherapy, 1-352.

O'Nions, E., Petersen, I., Buckman, J. E., Charlton, R., Cooper, C., Corbett, A., ... & Stott, J. (2023). Autism in England: assessing underdiagnosis in a population-based cohort

study of prospectively collected primary care data. *The Lancet Regional Health–Europe*, *29*.

Ouzzani, M., Hammady, H., Fedorowicz, Z., & Elmagarmid, A. (2016). Rayyan—a web and mobile app for systematic reviews. Systematic reviews, 5, 1-10.

Pelikan, J. M., Ganahl, K., Van den Broucke, S., & Sørensen, K. (2019). Measuring health literacy in Europe: introducing the European health literacy survey questionnaire (HLS-EU-Q). In *International handbook of health literacy* (pp. 115-138). Policy Press.

Peterson, J. L., Earl, R. K., Fox, E. A., Ma, R., Haidar, G., Pepper, M., Berliner, L., Wallace, A. S., & Bernier, R. A. (2019). Trauma and Autism Spectrum Disorder: Review, Proposed Treatment Adaptations and Future Directions. *Journal of Child & Adolescent Trauma*, *12*(4), 529–547. https://doi.org/10.1007/s40653-019-00253-5

Rubenstein, E., & Furnier, S. (2021). # Bias: The opportunities and challenges of surveys that recruit and collect data of autistic adults online. *Autism in Adulthood*, *3*(2), 120-128.

Rumball, F. (2019). A Systematic Review of the Assessment and Treatment of Posttraumatic Stress Disorder in Individuals with Autism Spectrum Disorders. *Review Journal of Autism and Developmental Disorders*, *6*(3), 294–324. https://doi.org/10.1007/s40489-018-0133-9

Rumball, F., Brook, L., Happé, F., & Karl, A. (2021). Heightened risk of posttraumatic stress disorder in adults with autism spectrum disorder: The role of cumulative trauma and memory deficits. *Research in Developmental Disabilities*, *110*, 103848. https://doi.org/10.1016/j.ridd.2020.103848

Sangha, O., Stucki, G., Liang, M. H., Fossel, A. H., & Katz, J. N. (2003). The Self-Administered Comorbidity Questionnaire: a new method to assess comorbidity for clinical and health services research. *Arthritis Care & Research: Official Journal of the American College of Rheumatology*, *49*(2), 156-163.

Shalev, A. Y., Gevonden, M., Ratanatharathorn, A., Laska, E., van der Mei, W. F., Qi, W., Lowe, S., Lai, B. S., Bryant, R. A., Delahanty, D., Matsuoka, Y. J., Olff, M., Schnyder,

U., Seedat, S., deRoon-Cassini, T. A., Kessler, R. C., & Koenen, K. C. (2019). Estimating the risk of PTSD in recent trauma survivors: results of the International Consortium to Predict PTSD (ICPP). *World Psychiatry*, *18*(1), 77–87. https://doi.org/10.1002/wps.20608

Stewart, G. R., Corbett, A., Ballard, C., Creese, B., Aarsland, D., Hampshire, A., ... & Happé, F. (2022). Traumatic life experiences and post-traumatic stress symptoms in middle-aged and older adults with and without autistic traits. International journal of geriatric psychiatry, 37(2).

Varcin, K. J., Herniman, S. E., Lin, A., Chen, Y., Perry, Y., Pugh, C., ... & Wood, S. J. (2022). Occurrence of psychosis and bipolar disorder in adults with autism: A systematic review and meta-analysis. *Neuroscience & Biobehavioral Reviews*, *134*, 104543.

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

Appendices

Appendix 1: Joint project statement

As discussed in the joint project statement subheading of the methodology section in Part 2, this was a joint project with another DClinPsy trainee, AG. Together, AG and I worked on the ethics application, online survey, consent forms, participant information sheets, and poster. We also recruited from the same pool of participants who completed the online survey, but we had different research questions and conducted separate interviews with different participants. This was because AG's research was focused on the healthcare experiences of autistic women aged 50 years or over, while mine was focused on the healthcare experiences of autistic older adults aged 65 years or over. Moreover, while AG and I carried out bracketing interviews with each other and second-coded each other's transcripts, we did not collaborate on any other aspects of the data analysis or thesis write-up.

Appendix 2a: Risk of bias domain items and coding manuals

	Potential sources of bias	Criteria to judge overall risk
Case-control	**Selection** 1. Is the case definition adequate? 2. Representativeness of the cases 3. Selection of controls 4. Definition of controls **Comparability** 1. Comparability of cases and controls on the basis of the design or analysis **Exposure** 1. Ascertainment of exposure 2. Non-response rate	High risk: 0–3 Medium risk: 4–6 Low risk: 7–9
Cohort	**Selection** 1. Representativeness of the exposed cohort 2. Selection of the non-exposed cohort 3. Ascertainment of exposure 4. Demonstration that outcome of interest was not present at the start of the study **Comparability** 1. Comparability of Cohorts on the Basis of the Design or Analysis **Outcome** 1. Assessment of outcome 2. Was follow-up long enough for outcomes to occur 3. Adequacy of follow-up of cohorts	High risk: 0–3 Medium risk: 4–6 Low risk: 7–9
Cross-sectional	**Selection** 1. Representativeness of the sample 2. Sample size 3. Non-respondents 4. Ascertainment of the exposure **Comparability** 1. Comparability of subjects in different outcome groups on the basis of design or analysis. Confounding factors controlled. **Outcome** 1. Assessment of outcome 2. Statistical test	Very Good Studies: 9-10 Good Studies: 7-8 Satisfactory Studies: 5-6 Unsatisfactory Studies: 0-4

Appendix 2b: Coding manual for case control studies

SELECTION

1) Is the Case Definition Adequate?

a) Requires some independent validation * (e.g. >1 person/record/time/process to extract information, or reference to primary record source such as x-rays or medical/hospital records) (Case e.g., Autism - Requires some independent validation, e.g., formal ssessment/interviews/observation via experienced clinician/research reliable examiner or also comparing this with medical/hospital records)

b) Record linkage (e.g. ICD codes in database) or self-report with no reference to primary record (e.g., ICD codes in database or based on self-reports or ascertained by interview with significant other)

c) No description (e.g., only reported that this was an ASD group)

2) Representativeness of the Cases

a) All eligible cases with outcome of interest over a defined period of time, all cases in a defined catchment area, all cases in a defined hospital or clinic, group of hospitals, health maintenance organisation, or an appropriate sample of those cases (e.g. random sample)*

b) Not satisfying requirements in part (a), or not stated.

3) Selection of Controls

This item assesses whether the control series used in the study is derived from the same population as the cases and essentially would have been cases had the outcome been present.

a) Community controls (i.e. same community as cases and would be cases if had outcome)* (also include GP records and national health records)

b) Hospital controls, within same community as cases (i.e. not another city) but derived from a hospitalised population

c) No description

4) Definition of Controls

a) no history of disease (endpoint)* (e.g., have never had diagnosis of ASD previously or self-reported ASD/ASD symptoms)

b) no description of source

COMPARABILITY

1) Comparability of Cases and Controls on the Basis of the Design or Analysis

A maximum of 2 stars can be allotted in this category

1) Comparability of cases and controls on the basis of the design or analysis

a) study controls for Sex (Select the most important factor.)*

b) study controls for any additional factor e.g, Age (This criteria could be modified to indicate specific control for a second important factor.)*

EXPOSURE

1) Ascertainment of exposure

a) secure record (e.g., diagnosis accepted via electronic data base; ICD-10 via registers) *

b) structured interview where blind to case/control status (e.g., K-SADS, SCID-I, Clinical Assessment)*

c) interview not blinded to case/control status (e.g., K-SADS, SCID-I, Clinical Assessment)

d) written self-report or medical record only (e.g., self-diagnosed PTSD or reporting of symptoms)
e) no description

2) Same method of ascertainment for cases and controls (this is just asking whether the same measures were used for both groups)
a) yes*
b) no

3) Non-Response rate (this is essentially checking if there is any missing data)
a) same rate for both groups*
b) non-respondents described
c) rate different and no designation

Appendix 2c: Coding manual for cohort studies

SELECTION

1) Representativeness of the exposed cohort

a) truly representative of the average ASC population in the community ***** (e.g., all cases in a defined catchment area, all cases in a defined hospital or clinic, group of hospitals, health maintenance organisation, or an appropriate sample of those cases (e.g. random sample))
b) somewhat representative of the average ASC population in the community *****
c) selected group of users eg nurses, volunteers
d) no description of the derivation of the cohort

2) Selection of the non-exposed cohort (this only applies if there is a comparison group)

a) drawn from the same community as the exposed cohort *****
b) drawn from a different source
c) no description of the derivation of the non exposed cohort

3) Ascertainment of exposure

a) secure record (eg surgical records) ***** (medical, hospital records)
b) structured interview ***** (e.g., independent validation, e.g., formal assessment/interviews/observation via experienced clinician/research reliable examiner)
c) written self-report
d) no description

4) Demonstration that outcome (PTSD) of interest was not present at start of study

a) yes *****
b) no

COMPARABILITY

1) Comparability of cohorts on the basis of the design or analysis

a) study controls for general characteristics (select the most important factor) *****
b) study controls for any additional factor ***** (This criteria could be modified to indicate specific control for a second important factor.)

OUTCOME

1) Assessment of outcome

a) independent blind assessment ***** (e.g., K-SADS, SCID-I, Clinical Assessment)
b) record linkage ***** (Via medical/hospital records, electronic database)
c) self report (e.g., self diagnosed ptsd/symptoms)
d) no description

2) Was follow-up long enough for outcomes to occur

a) yes (select an adequate follow up period for outcome of interest)***** (depends on aims of study)
b) no

3) Adequacy of follow up of cohorts

a) complete follow up - all subjects accounted for *****
b) subjects lost to follow up unlikely to introduce bias - small number lost - >10% (select an adequate %) follow up, or description provided of those lost) *****
c) follow up rate <20% (select an adequate %) and no description of those lost
d) no statement

Appendix 3: Risk of bias scoring table

Study	Potential sources of bias considered								Overall RoB summary
	Selection				Comparability	Exposure			
	1	2	3	4	1	1	2	3	
Case-control									
Hoch and Youssef (2020)	*	*	*	*	-	*	*	*	Low
Nimmo-Smith et al. (2020)	*	*	*	*	**	*	*	*	Low
Underwood et al. (2019)	*	*	*	*	**	-	*	*	Low
Hollocks, Pickles, Howlin & Simonoff (2016)	*	*	-	*	-	*	*	*	Medium
Lever & Geurts (2016)	*	*	-	*	-	*	*	*	Medium
Reinvall et al. (2016)	*	*	-	*	-	*	*	*	Medium
Russell et al. (2016)	*	*	*	*	-	*	*	*	Low
Bitsika and Sharpley (2015)	*	*	*	-	-	*	*	*	Medium
Orinstein et al. (2015)	*	*	*	*	-	*	*	*	Low
Joshi et al. (2013)	*	*	-	*	**	*	*	-	Low
van Steensel, Bögels, and de Bruin (2013)	*	-	*	*	-	*	*	*	Medium
Rydén and Bejerot (2008)	*	*	*	*	-	-	*	*	Medium
	Selection				Comparability	Outcome			
	1	2	3	4	1	1	2	3	
Cohort									
Gillberg, Helles, Billstedt, and Gillberg (2016)	-	N/A[b]	*	-	N/A[a]	*	*	-	High
Verheij et al. (2015)	-	N/A[b]	-	*	N/A[a]	*	*	*	Medium
Mehtar and Mukaddes (2011)	-	N/A[b]	*	-	N/A[a]	*	*	*	Medium
Bryson, Corrigan, Mcdonald, and Holmes (2008)	*	*	*	-	-	*	*	*	Medium
	Selection				Comparability	Outcome			
	1	2	3	4	1	1	2		
Cross-sectional									
Brenner et al. (2018)	*	-	*	*	**	-	*		Good
Plesa Skwerer et al. 2018	*	-	*	**	N/A[c]	**	*		Good
Mansour et al. (2017)	*	-	*	**	N/A[c]	**	*		Good
Taylor and Gotham (2016)	*	-	*	**	N/A[c]	**	*		Good
Roy, Prox-Vagedes, Ohlmeier, and Dillo (2015)	-	-	*	-	N/A[c]	**	-		Unsatisfactory
Joshi et al. (2014)	*	-	*	**	-	**	*		Good
Kusaka et al. (2014)	*	-	*	**	N/A[c]	**	*		Good
Hofvander et al. (2009)	*	-	*	**	N/A[c]	**	*		Good

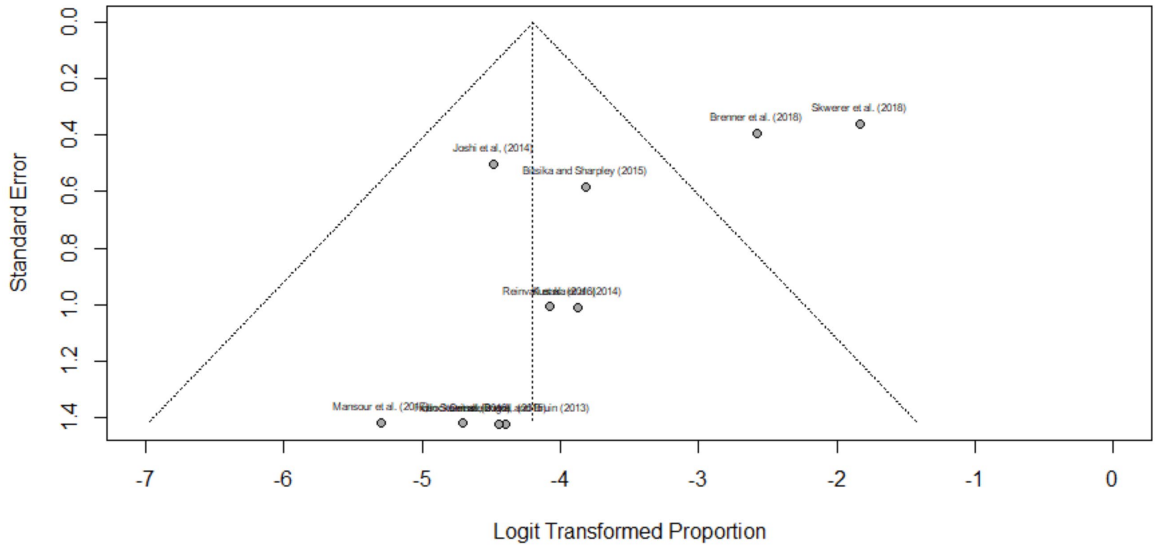
[a]Comparability of cohorts on the basis of the design or analysis was not possible as there was only one cohort and therefore no comparison cohort.

[b]Not applicable as there was no non-exposed cohort

[C] Comparability of subjects in different outcome groups on the basis of design or analysis was not possible as there was only one outcome group and therefore no other outcome group to draw comparisons.

- No star awarded

Appendix 4a: Funnel plot for child and adolescent current prevalence

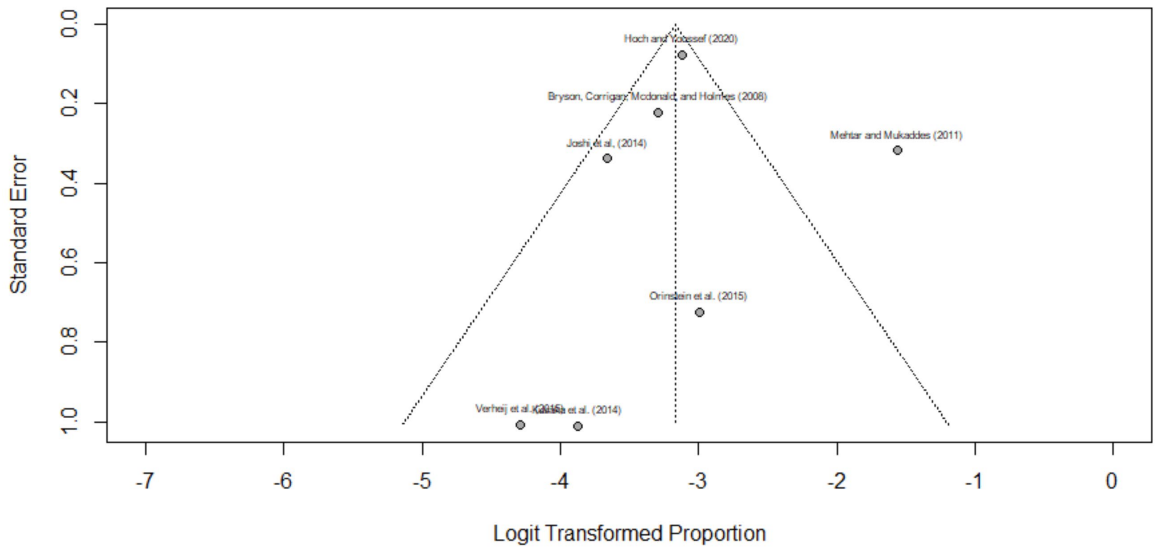


Appendix 4b: Subgroup analysis for child and adolescent current prevalence

Child and Adolescence Current PTSD Proportion	No. Studies	No. Events	Total No.	Proportion (95% CI)	Q	t^2	I^2, %	*p*	The P-value for subgroup differences
Region									
Europe	3	1	155	0.0065 (0.0009; 0.0443)	0.00	0	0.0%	1.00	0.5168, Q = 1.32
North America	4	11	600	0.0107 (0.0016; 0.0683)	9.00	1.6986	66.7%	0.03	
Other	2	4	189	0.0212 (0.0080; 0.0550)	0.00	0	0.0%	0.97	
Study Type									
Case-Control	5	4	337	0.0119 (0.0045; 0.0312)	0.05	0	0.0%	1	0.6972, Q = 0.15
Cross-Sectional	4	12	607	0.0163 (0.0045; 0.0568)	9.29	0.9547	67.7%	0.03	
Sampling Source									
Community	1	3	140	0.0214 (0.0069; 0.0643)	0.00	-	-	-	0.9299, Q = 0.15
Referrals	6	13	663	0.0159 (0.0056; 0.0445)	9.77	0.6451	48.8%	0.08	
Mixture	2	0	141	0.0000 (0.0000; 1.0000)	0.00	0	0.0%	1.00	
Gender (% Male)									
≤ 80%	4	9	307	0.0186 (0.0044; 0.0749)	2.97	0.9404	0.0%	0.40	0.5231, Q = 0.41
> 80%	5	7	637	0.0110 (0.0052; 0.0229)	0.75	0	0.0%	0.94	
Ethnicity (% White)									
≤ 85%	1	0	99	0.0000 (0.0000; 1.0000)	0.00	-	-	-	0.6844, Q = 0.76
> 85%	4	14	641	0.0207 (0.0078; 0.0537)	9.62	0.5376	68.8%	0.02	
Not Reported	4	2	204	0.0098 (0.0025; 0.0383)	0.02	0	0.0%	1.00	
Presence of ID									
Yes	4	11	598	0.0108 (0.0016; 0.0683)	9.00	1.6749	66.7%	0.03	0.7857, Q = 0.07
No	5	5	346	0.0145 (0.0060; 0.0342)	0.05	0	0.0%	1	
PTSD Diagnostic Criteria									
DSM-III	1	4	360	0.0111 (0.0042; 0.0292)	0.00	-	-	-	0.1574, Q = 6.62
DSM-IV	4	1	230	0.0043 (0.0006; 0.0302)	0.00	0	0.0%	1.00	
DSM-V	2	10	239	0.0408 (0.0177; 0.0911)	3.14	0.1570	68.1%	0.08	
ICD-10	1	1	60	0.0167 (0.0023; 0.1090)	0.00	-	-	-	
Not Reported	1	0	55	0.0000 (0.0000; 1.0000)	0.00	-	-	-	
PTSD Assessment Method									
KID-SCID	2	3	180	0.0167 (0.0054; 0.0504)	0.00	0	0.0%	1	**0.0402, Q = 11.63**
CASI-5	1	7	99	0.0707 (0.0341; 0.1410)	0.00	-	-	-	
DICA-IV	1	0	99	0.0000 (0.0000; 1.0000)	0.00	-	-	-	
DAWBA	1	1	60	0.0167 (0.0023; 0.1090)	0.00	-	-	-	
CAPA	1	0	55	0.0000 (0.0000; 1.0000)	0.00	-	-	-	
K-SADS	3	5	451	0.0111 (0.0046; 0.0264)	0.3	0	0.0%	0.86	
Respondent									
Parent	8	16	904	0.0139 (0.0055; 0.0345)	10.18	0.6363	31.3%	0.18	0.9997,

Combined (child and parent)	1	0	40	0.0000 (0.0000; 1.0000)	0.00	-	-	-	Q = 0

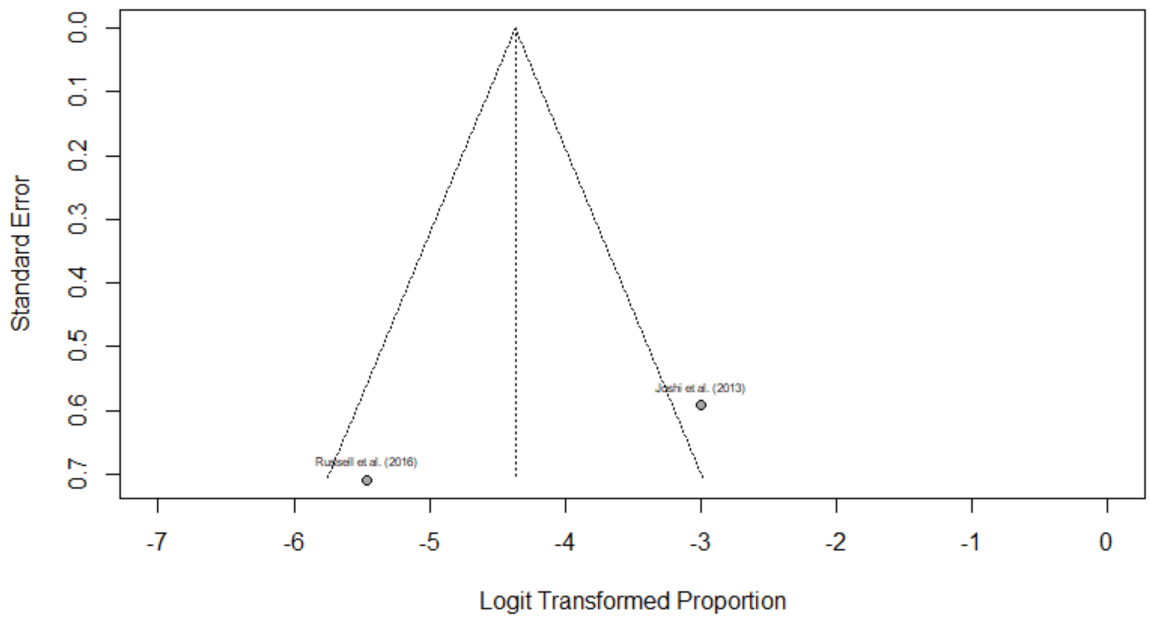
Appendix 5a: Funnel plot for child and adolescent lifetime prevalence



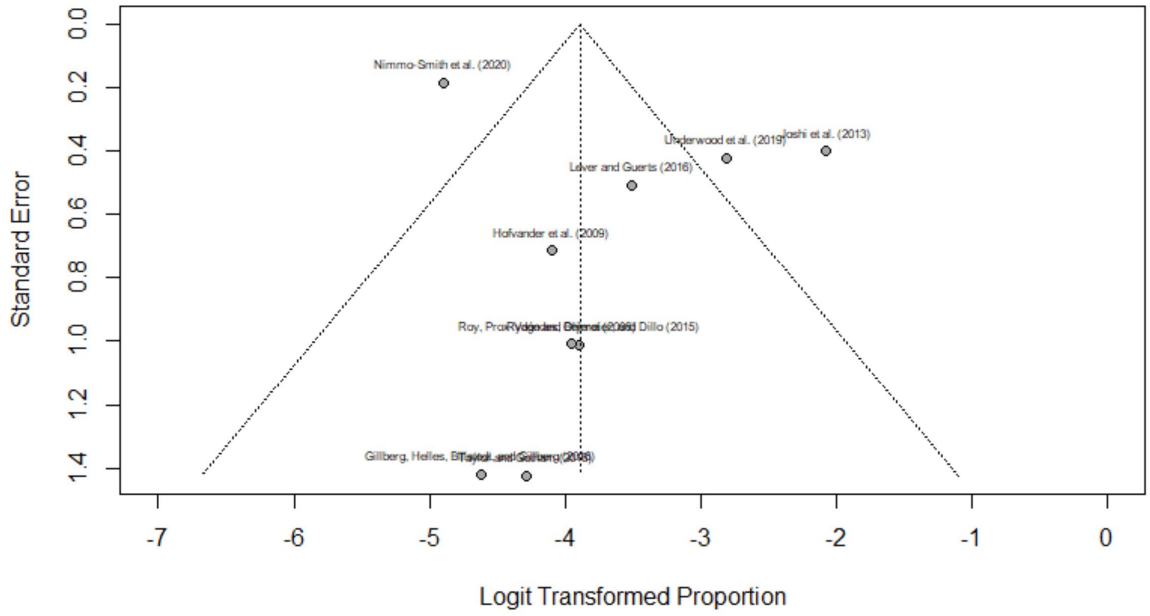
Appendix 5b: Subgroup analysis for child and adolescent lifetime prevalence

Child and Adolescence Lifetime PTSD Proportion	No. Studies	No. Cases	Total No.	Prevalence, % (95% CI)	Q	t^2	I^2, %	p	P-value for subgroup differences
Region									
Europe	1	1	74	0.0135 (0.0019; 0.0897)	0.00	-	-	-	0.4205, Q = 1.73
North America	4	215	5294	0.0406 (0.0356; 0.0463)	2.98	0	0.0%	0.39	
Other	1	1	49	0.0204 (0.0029; 0.1311)	0.00	-	-	-	
Study Type									
Cross-Sectional	3	31	995	0.0312 (0.0220; 0.0440)	1.05	0	0.0%	0.59	0.1394, Q = 3.94
Case-Control	2	185	4348	0.0425 (0.0369; 0.0490)	0.03	0	0.0%	0.87	
Longitudinal	1	1	74	0.0135 (0.0019; 0.0897)	0.00	-	-	-	
Sampling Source									
Electronic Hospital Records	2	204	4892	0.0417 (0.0364; 0.0477)	0.57	0	0.0%	0.45	0.1334, Q = 4.03
Referrals	3	11	483	0.0228 (0.0127; 0.0406)	0.37	0	0.0%	0.83	
Mixture	1	2	42	0.0476 (0.0119; 0.1714)	0.00	-	-	-	
Gender (% Male)									
≤ 80%	2	184	4355	0.0423 (0.0367; 0.0486)	0.56	0	0.0%	0.46	0.0972, Q = 2.75
> 80%	4	33	1062	0.0311 (0.0222; 0.0434)	1.94	0	0.0%	0.59	
Ethnicity (% White)									
≤ 85%	2	204	4892	0.0417 (0.0364; 0.0477)	0.57	0	0.0%	0.45	0.1759, Q = 3.48
> 85%	3	12	476	0.0252 (0.0144; 0.0439)	1.20	0	0.0%	0.55	
Not Reported	1	1	49	0.0204 (0.0029; 0.1311)	0.00	-	-	-	
Presence of ID									
Yes	3	31	1020	0.0304 (0.0215; 0.0429)	1.59	0	0.0%	0.45	0.1985, Q = 3.23
No	2	3	91	0.0330 (0.0107; 0.0973)	0.50	0	0.0%	0.48	
NR	1	183	4306	0.0425 (0.0369; 0.0489)	0	-	-	-	
PTSD Diagnostic Criteria									
DSM-IV	4	25	751	0.0333 (0.0226; 0.0488)	1.44	0	0.0%	0.70	0.1634, Q = 3.62
DSM-IV, DSM-V, ICD-9, ICD-10	1	183	4306	0.0425 (0.0369; 0.0489)	0	-	-	-	
DSMII, DSM-IV	1	9	360	0.0250 (0.0131; 0.0473)	0	-	-	-	
PTSD Assessment Method									
Electronic Hospital Records	2	204	4892	0.0417 (0.0364; 0.0477)	0.57	0	0.0%	0.45	0.1624, Q = 3.64
DISC-IV	1	1	74	0.0135 (0.0019; 0.0897)	0	-	-	-	
K-SADS	3	12	451	0.0266 (0.0152; 0.0463)	0.79	0	0.0%	0.67	
Respondent									
Parent	4	13	525	0.0248 (0.0144; 0.0422)	1.26	0	0.0%	0.74	0.0630, Q = 3.46
Not Reported	2	204	4892	0.0417 (0.0364; 0.0477)	0.57	0	0.0%	0.45	

Appendix 6: Funnel plot for adult current prevalence



Appendix 7a: Funnel plot for adult lifetime prevalence

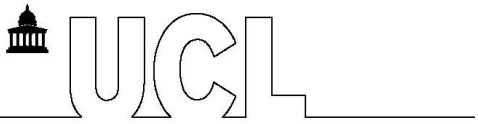


Appendix 7b: Subgroup analysis for adult lifetime prevalence

Adult Lifetime PTSD Proportion	No. Studies	No. Cases	Total No.	Prevalence, % (95% CI)	Q	t^2	I^2, %	p	P-value for subgroup differences
Region									
Europe	7	44	4567	0.0165 [0.0083; 0.0326)	25.48	0.42	76.5%	<0.01	0.9997,
North America	1	0	36	0.0000 (0.0000; 1.0000)	0.00	-	-	-	Q = 0.00
Study Type									
Cross-Sectional	3	3	208	0.0144 (0.0047; 0.0437)	0.03	0	0%	0.99	0.9238,
Case-Control	4	41	4345	0.0193 (0.0079; 0.0466)	24.97	0.5707	88%	<0.01	Q = 0.16
Longitudinal	1	0	50	0.0000 (0.0000; 1.0000)	0.00	-	-	-	
Sampling Source									
Registry-based cohort	1	30	4049	0.0074 (0.0052; 0.0106)	0.00	-	-	-	**0.0096,**
Referrals	5	10	380	0.0237 (0.0100; 0.0552)	3.40	0.1612	0%	0.49	**Q = 9.29**
Mixture	2	4	174	0.0230 (0.0087; 0.0596)	0.00	0	0%	1.00	
Gender (% Male)									
≤ 68%	4	34	4274	0.0080 (0.0057; 0.0111)	2.78	0	0.0%	0.43	**0.0287,**
> 68%	4	10	329	0.0275 (0.0095; 0.0766)	1.15	0.3513	0.0%	0.76	**Q = 4.79**
Ethnicity (% White)									
> 90%	2	6	141	0.0426 (0.0192; 0.0915)	0.00	0	0.0%	1.00	**0.0156,**
Not Reported	6	38	4462	0.0113 (0.0054; 0.0233)	8.50	0.1472	41.2%	0.13	**Q = 5.85**
Presence of ID									
Yes	2	30	4085	0.0073 (0.0051; 0.0105)	0.00	0	0.0%	1.00	**0.005,**
No	4	9	330	0.0236 (0.0087; 0.0622)	3.01	0.2300	0.3%	0.39	**Q = 10.55**
NR	2	5	188	0.0266 (0.0111; 0.0623)	0.11	0	0.0%	0.74	
PTSD Diagnostic Criteria									
DMS-IV	6	8	449	0.0178 (0.0089; 0.0352)	0.51	0	0.0%	0.99	0.9659,
ICD-10	2	36	4154	0.0184 (0.0045; 0.0725)	20.85	0.9263	95.2%	<0.01	Q = 0.00
PTSD Assessment Method									
MINI	2	4	188	0.0213 (0.0080; 0.0553)	0.00	0	0.0%	1.00	0.9998,
Electronic Hospital Records	2	36	4154	0.0184 (0.0045; 0.0725)	20.85	0.9263	95.2%	<0.01	Q = 0.10
SCID	1	1	50	0.0200 (0.0028; 0.1288)	0.00	-	-	-	
Clinical Evaluation	1	1	53	0.0189 (0.0027; 0.1221)	0.00	-	-	-	
SCID and Clinical Interview	1	2	122	0.0164 (0.0041; 0.0632)	0.00	-	-	-	
K-SADS	1	0	36	0.0000 (0.0000; 1.0000)	0.00	-	-	-	
Respondent									
Self	3	7	310	0.0226 (0.0108; 0.0466)	0.47	0	0.0%	0.79	0.7919,
Parent	1	0	36	0.0000 (0.0000; 1.0000)	0.00	-	-	-	Q = 0.47
Not reported	4	37	4257	0.0143 (0.0049; 0.0416)	21.21	0.8527	85.9%	< 0.01	

Appendix 8: Ethical approval letter

UCL RESEARCH ETHICS COMMITTEE
OFFICE FOR THE VICE PROVOST RESEARCH



4th April 2022

Dr Joshua Stott
Research Department of Clinical, Educational and Health Psychology
UCL

Cc: Amy Gillions and Hassan Mansour, UCL Research Department of Clinical, Educational and Health Psychology

Dear Dr Stott

Notification of Ethics Approval with Provisos
Project ID/Title: 22117/001: Understanding the views of autistic people aged 50 or over on their healthcare need

Further to your satisfactory responses to the Committee's comments, I am pleased to confirm in my capacity as Chair of the UCL Research Ethics Committee (REC) that your study has been ethically approved by the UCL REC until **1st November 2023.**

Ethical approval is subject to the following conditions:

Notification of Amendments to the Research
You must seek Chair's approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing an 'Amendment Approval Request Form' https://www.ucl.ac.uk/research-ethics/responsibilities-after-approval

Adverse Event Reporting – Serious and Non-Serious
It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator (ethics@ucl.ac.uk) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Joint Chairs will decide whether the study should be terminated pending the opinion of an independent expert. For non-serious adverse events the Joint Chairs of the Ethics Committee should again be notified via the Ethics Committee Administrator within ten days of the incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol.

The Joint Chairs will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

Office of the Vice Provost Research, 2 Taviton Street
University College London
Tel: +44 (0)20 7679 8717
Email: ethics@ucl.ac.uk
http://ethics.grad.ucl.ac.uk/

Final Report

At the end of the data collection element of your research we ask that you submit a very brief report (1-2 paragraphs will suffice) which includes in particular issues relating to the ethical implications of the research i.e. issues obtaining consent, participants withdrawing from the research, confidentiality, protection of participants from physical and mental harm etc.

In addition, please:

- ensure that you follow all relevant guidance as laid out in UCL's Code of Conduct for Research;
- note that you are required to adhere to all research data/records management and storage procedures agreed as part of your application. This will be expected even after completion of the study.

With best wishes for the research.

Yours sincerely

Professor Lynn Ang
Joint Chair, UCL Research Ethics Committee

Appendix 9a: Online survey

Example Qualtrics Survey

We have created a mock template of the questionnaire on Qualtrics. Please note this is subject to change based on feedback from autistic service users/experts by experience. They will provide feedback on the accessibility of the format, the questionnaires included and length. The information sheets and consent forms will be embedded within Qualtrics but have been attached in the appendix separately for the purposes of this ethics application.

If someone is supporting you to complete the questionnaire, what is their relationship to you?

- ○ Parent (Mother)
- ○ Parent (Father)
- ○ Sibling
- ○ Grandparent
- ○ Cousin
- ○ Carer
- ○ Friend
- ○ Partner
- ○ Spouse
- ○ Other: _____

What is your age? (Please note we are only looking to recruit autistic adults aged 50 years or over)

- ○ 50 – 100 (will be a drop down menu)

How would you describe your gender?

- ○ Male
- ○ Female
- ○ Non-binary
- ○ Prefer not to say

Is your gender the same as registered at birth?

- ○ Yes
- ○ No
- ○ Prefer not to say

How would you describe your sexual orientation?

- ○ Heterosexual
- ○ Homosexual (Gay/Lesbian)
- ○ Bisexual
- ○ Asexual
- ○ Prefer not to say
- ○ Other: _____

How would you describe your ethnicity?

- ○ White: English, Welsh, Scottish, Northern Irish or British
- ○ White: Irish
- ○ White: Gypsy or Irish Traveller
- ○ Any other White background

_____

- ○ Mixed or Multiple ethnic groups: White and Black Caribbean
- ○ Mixed or Multiple ethnic groups: White and African Caribbean
- ○ Mixed or Multiple ethnic groups: White and Asian
- ○ Any other Mixed or Multiple ethnic background

_____

- ○ Asian or Asian British: Indian
- ○ Asian or Asian British: Pakistani
- ○ Asian or Asian British: Bangladeshi
- ○ Asian or Asian British: Chinese
- ○ Any other Asian background

_____

- ○ Black, African, Caribbean or Black British: African
- ○ Black, African, Caribbean or Black British: Caribbean
- ○ Any other Black, African, Caribbean or Black British background

_____

- ○ Arab
- ○ Other: _____

What is your marital status?

- ○ Single
- ○ Married
- ○ Widowed/Widower
- ○ Civil Partnership
- ○ Other: _____

Page Break

Do you have a diagnosis of autism?

- ○ Yes, I have a formal diagnosis from a healthcare professional
- ○ No, but I self-identify as autistic
- ○ No, I do not have a diagnosis and do not self-identify as being autistic

What age were you diagnosed with autism/started to self-identify as autistic?

- ○ 0-10
- ○ 10-15
- ○ 15-20
- ○ 20-30
- ○ 30-40
- ○ 40-50
- ○ 50-60
- ○ 60-70
- ○ 70-80
- ○ 80+

Is there anything else you would like to tell us about your diagnosis or self-identification with autism? Here are some prompts you may wish to think about: Your experience of getting an autism diagnosis,

- Any obstacles to getting diagnosed
- Or,
- How you came to self-identify as autistic
- Barriers to seeking a formal diagnosis

_____

_____

_____

_____

_____

Do you have an intellectual disability?

- ○ No
- ○ Yes, I have a formal diagnosis from a healthcare professional
- ○ Yes, I self-identify as having an intellectual disability

---

If you answered yes to the previous question, how would you describe your intellectual disability?

- ○ Mild
- ○ Moderate
- ○ Severe
- ○ Multiple and Profound

Page Break

Carer Information:

Do you have a formal carer?

- ○ Yes
- ○ No

If you answered yes to the question above, please describe the role of your carer and their relationship to you:

_____

_____

_____

_____

_____

Do you receive any informal support from a family member or friend in regards to your healthcare?

- ○ Yes
- ○ No

If you answered yes to the question above, please describe the role of your supporter and their relationship to you:

_____

_____

_____

_____

_____

End of Block: Demographics

Start of Block: Education, Living Status

Education, Employment and Living Status:

What is your highest level of education?

- ○ School up to age 16
- ○ School up to age 18
- ○ Undergraduate degree
- ○ Postgraduate degree
- ○ Doctoral degree
- ○ Did not complete formal education

Who do you live with?

- ○ Alone
- ○ With spouse or partner
- ○ With relatives
- ○ With friends
- ○ In residential accommodation
- ○ Other _____

What is your employment status?

- ○ Employed (part-time)
- ○ Employed (full-time)
- ○ Unemployed
- ○ Retired
- ○ Volunteer

End of Block: Education, Living Status

Start of Block: AQ-10

Autism Traits Questionnaire:
Select the option on each line that best matches your answer (one only).

	Definitely Agee	Slightly Agree	Slightly Disagree	Definitely Disagree
I often notice small sounds when others do not	○	○	○	○
I usually concentrate on the whole picture, rather than the small details	○	○	○	○
I find it easy to do more than one thing at once	○	○	○	○
If there is an interruption, I can switch back to what I was doing very quickly	○	○	○	○
I find it easy to 'read between the lines' when someone is talking to me	○	○	○	○
I know how to tell if someone listening to me is getting bored	○	○	○	○
When I'm reading a story I find it difficult to work out the characters' intentions	○	○	○	○

I like to collect information about categories of things (e.g. types of car, types of bird, types of train, types of plant etc)	○	○	○	○
I find it easy to work out what someone is thinking or feeling just by looking at their face	○	○	○	○
I find it difficult to work out people's intentions	○	○	○	○

End of Block: AQ-10

Start of Block: Health Literacy Questionnaire (SF-16)

Here are some questions about how it is for you to find, understand and use information related to health, illness and medical care. Select the option on each line that best matches your answer (one only).

	Very Easy	Easy	Difficult	Very Difficult	Don't know
How easy/difficult is it for you to find information on treatments of illnesses that concern you?	○	○	○	○	○
How easy/difficult is it for you to find out where to get professional help when you are ill (e.g. doctor, pharmacist or psychologist)?	○	○	○	○	○
How easy/difficult is it for you to understand what your doctor says to you?	○	○	○	○	○
How easy/difficult is it for you to understand your doctor´s or pharmacist´s instruction on how to take a prescribed medicine?	○	○	○	○	○

How easy/difficult is it for you to judge when you need to a second opinion from another doctor?	○	○	○	○	○
How easy/difficult is it for you to use the information the doctor gives you to make decisions about your illness?	○	○	○	○	○
How easy/difficult is it for you to follow instructions from your doctor or pharmacist?	○	○	○	○	○
How easy/difficult is it for you to find information on how to manage mental health problems such as stress and depression?	○	○	○	○	○

How easy/difficult is it for you to understand warnings about behaviour (e.g. smoking, low physical activity and drinking too much)?	○	○	○	○	○
How easy/difficult is it for you to understand why you need health screenings (such as breast exam, blood sugar- or blood pressure test)?	○	○	○	○	○
How easy/difficult is it for you to judge if the informa¬tion on health risks in the media is reliable (e.g. from TV or internet)?	○	○	○	○	○

How easy/difficult is it for you to decide how you can protect yourself from illness based on information in media (e.g. newspapers, leaflets and internet)?	○	○	○	○	○
How easy/difficult is it for you to find out about activities that are good for your mental well-being (e.g. meditation, exercise and walking)?	○	○	○	○	○
How easy/difficult is it for you to understand advice on health from your family members or friends?	○	○	○	○	○

How easy/difficult is it for you to understand information in the media on how to get healthier (e.g. from the internet, daily or weekly magazines)?	○	○	○	○	○
How easy/difficult is it for you to judge which everyday behaviour is related to your health (e.g. eating habits, exercise habits and drinking habits)?	○	○	○	○	○

End of Block: Health Literacy Questionnaire (SF-16)

Start of Block: Self-administered comorbidity

The following is a list of common problems. Please indicate if you currently have the problem in the first column. If you do not have the problem, answer 'no' and skip to the next problem.
If you do have the problem, please indicate if you receive medications or some other type of treatment for the problem. In the third column, indicate if the problem limits any of your activities. Finally, indicate all medical conditions that are not listed under "other medical problems" at the end of the page.

	Do you have the problem?		Do you receive treatment for it?		Does it limit your activities?	
	No	Yes	No	Yes	No	Yes

Heart disease	○	○	○	○	○	○
High blood pressure	○	○	○	○	○	○
Lung disease	○	○	○	○	○	○
Diabetes	○	○	○	○	○	○
Ulcer or stomach disease	○	○	○	○	○	○
Kidney disease	○	○	○	○	○	○
Liver disease	○	○	○	○	○	○
Anaemia or other blood disease	○	○	○	○	○	○
Cancer	○	○	○	○	○	○
Depression	○	○	○	○	○	○
Osteoarthritis, degenerative arthritis	○	○	○	○	○	○
Back pain	○	○	○	○	○	○
Rheumatoid arthritis	○	○	○	○	○	○
Other medical problem	○	○	○	○	○	○
Other medical problem	○	○	○	○	○	○
Other medical problem	○	○	○	○	○	○

Other medical problem	○	○	○	○	○	○
Other medical problem	○	○	○	○	○	○

End of Block: Self-administered comorbidity

Start of Block: Block 8

Here are some open-ended questions about your experience of accessing healthcare services. Please give as much detail as you feel able to.

Do you have (or have you ever had) a diagnosis for any physical or mental health difficulties? If yes, then how easy was it to access support for these conditions?

_____

_____

_____

_____

_____

Do you currently or have you previously experienced any difficulties when accessing or engaging with healthcare services?

_____

_____

_____

_____

_____

What helps when trying to access, or engage with healthcare services?

_____

_____

_____

_____

_____

What could healthcare providers do to improve their level of care, particularly for autistic older adults?

_____

_____

_____

_____

_____

How have your healthcare needs changed over time?

_____

_____

_____

_____

_____

End of Block: Block 8

Start of Block: Interview Contact

We are also looking to interview some people who have completed this questionnaire to find out more about their healthcare needs and experiences of using healthcare services as an older autistic person. We are also interested in interviewing carers or supporters. If you would like to participate in an interview, please fill in your contact details and a member of the research team will be in touch. You will be provided with a separate information sheet and consent form. If you do not wish to take part in the interview stage, please leave this form blank and click the arrow to complete and submit the questionnaire.

What is your name?

_____

What is your email address?

_____

What is your mobile or landline telephone number?

_____

What is your preferred contact method (email or telephone)?

_____

What is your preferred day and time to be contacted?

_____

End of Block: Interview Contact

Appendix 9b: Participant information sheet for the online survey

RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL AND HEALTH PSYCHOLOGY

Autism and Ageing Research Project - Online Survey Information Sheet*

UCL Research Ethics Committee Approval ID Number: 22117/001

Study Title: Understanding the Healthcare Needs of Autistic Older Adults

Department: UCL Division of Psychology and Language Sciences

Research Team and Contact Details: Amy Gillions and Hassan Mansour (Trainee Clinical Psychologists), amy.gillions.20@ucl.ac.uk and hassan.mansour.17@ucl.ac.uk

Research Supervisors: Dr Joshua Stott and Dr Liz O'Nions

UCL Ethics Committee Contact Details: ethics@ucl.ac.uk

You are being invited to take part in a research project. Before you decide whether or not to participate, please read through this information sheet to find out what participation will involve. If you have any questions, please contact the research team using the information above.

Project overview
In the United Kingdom, very little is known about the healthcare needs of autistic adults aged 50 or over and their experiences of getting help with physical and mental health problems from the NHS or other services.

The aim of this study is to find out more about the healthcare needs of autistic people aged 50 or over. The research aims to explore things that help or hinder people in accessing healthcare. We hope that our findings will show how services can better meet the needs of autistic people aged 50 or over.

Who can be involved in the project?
We are inviting autistic adults aged 50 or over to take part. We welcome autistic people who have a formal diagnosis and those who self-identify as autistic. We also want to recruit people with intellectual disabilities and autism. You can take part by yourself or with some help from a friend, partner, supporter, or carer.

What does participating involve?
You will be asked to complete a survey. You can complete the survey anonymously. If you are interested in completing follow-up research, there will also be a section where you can provide your contact details.

During the survey you will be asked to provide information around your gender, ethnicity, age, and sexuality. This is to help us better understand the general demographic of those taking part in this study and if these characteristics impact on a person's experience of accessing healthcare support. You will also be asked to complete several questionnaires which will help us develop a better understand of your current healthcare needs as well as facilitators and barriers to accessing support.

If you find it difficult to access the online survey, please get in touch with a member of the research team by email or phone so that we can assist you. Our contact details are at the top of this page. If you struggle to use online surveys, we can complete the questions with you over the phone. Please contact us by phone to arrange this.

What will happen if I choose to participate?
If you choose to participate, you will be taken to the first page of the online survey automatically once you have given your consent. You can complete the survey at: https://uclpsych.eu.qualtrics.com/jfe/form/SV_1XO0GlVCBXeQ4wC

You do not have to answer all questions if you do not wish to and you can exit the survey at any time. At the end of the survey, you will be asked whether you would like to provide contact information so the research team can invite you to take part in another part of the research (an interview about your healthcare experiences).

If you provide your contact details, we will add you to the list of people to contact about doing an interview. There will be a separate information sheet and consent form for this part of the study. Please note that we will not be able to invite everyone who wants to do an interview.

If you do not wish to take part in an interview, you don't need to give us your contact details.

Are there any possible risks to taking part?
We do not expect there will be any risks to participating in our research. We have consulted autistic people to review our survey to make sure it is user-friendly. If you experience any distress at any point, please contact the research team. Our details are at the top of this sheet.

Are there any possible benefits to taking part?
Whilst there are no immediate benefits to taking part in the project, we hope that our findings will help us to better understand the healthcare needs of autistic adults aged 50 or over and their experiences of using healthcare services. Moreover, by fully completing the survey and providing your contact details you will be offered the chance to enter a prize draw to win one of five £20 vouchers.

How will survey information be stored?
Responses to the survey will initially be stored securely on the Qualtrics software servers. We will then move the data to a secure UCL computer drive. All data will be kept confidential. If you choose to take part anonymously, your data will not be linked to you personally.

What will happen to the results of the survey?

You can withdraw your results after completing the survey for up to 1-month. However, this will only be possible for those who also provided their contact details during the survey. All data collected in the survey will be anonymised, analysed and written up for the purposes of two doctoral theses completed by Amy and Hassan (research team). Following this, we also hope to publish the results in a research journal. We anticipate the project to be finished by September 2023.

Summary
This project aims to better understand the healthcare needs and experiences accessing healthcare services for autistic adults aged 50 or over using an online survey. We also want to interview some of the people who complete the survey.

If you have any questions that are not addressed in this information sheet, please contact the research team before completing the consent form.
**Please note this form will be embedded in the Qualtrics survey itself. It will be downloadable as a separate document as well.*

Appendix 9c: Consent form for the online survey

Consent Form (Online Survey)*

Please complete this form after you have read the Information Sheet on the previous page. If you have any questions then please contact the research team.

Before agreeing to completing the survey, please read all the following statements and tick each one you agree with:

		Tick Box
1.	I confirm that I have read and understood the information sheet.	
2.	I consent to participate in this study voluntarily and understand that I can stop completing the survey at any time.	
3.	I understand that I can complete the survey anonymously which means that the information I provide will not be identifiable as relating to me.	
4.	I understand that if I choose to provide my contact details at the end of the survey (optional), my data will not be anonymous but will remain confidential. If I choose to provide my contact details, I confirm that the research team can contact me about completing an interview for the purposes of this research project.	
5.	I understand that all survey information will be stored securely and will only be accessible to the research team.	
6.	I understand that I can choose to withdraw my responses for up to 1-months after completing the survey. However, this will not be possible if I complete it anonymously.	
7.	I am aware of the contact details of the research team if I have any concerns about the study.	
8.	I understand that UCL have legal basis to collect information about my health for 'public task' research purposes	

In addition,

- I confirm that I am aged 50 or above and I can confirm that I have been diagnosed autistic or I self-identify as autistic

**Please note this form will be embedded in the Qualtrics survey itself. We will include the UCL logo on the page.*

This will be the appearance of the process of consenting to the study. If participants do not consent, they will be redirected to the survey home page. Participants will be required to provide an answer to this question in order to continue the questionnaire.

Appendix 10: Poster

Autism and Ageing Research Study

UCL

Are you an autistic person aged 50 or over?

We are looking for autistic people to take part in our study. We want to understand more about the healthcare needs of autistic people aged 50 or over.

The study aims to explore the experiences of using healthcare services for autistic adults aged 50 or over. We want to explore barriers and facilitators to accessing services and how to overcome these barriers.

What does participating involve?
The two parts of our study are explained below.

Survey for autistic adults aged 50 or over:

- We are looking for people to complete a **short online survey** answering questions about their health and experience of using services.
- The survey can be completed anonymously, or you can provide contact details if you are interested in other parts of the study.

Interviews for autistic adults aged 50 or over:

- We are planning to **interview** some people about their healthcare needs and experiences.
- Interviews will take place over the phone or on Zoom/Teams and will be audio-recorded.
- You will receive a £15 voucher for taking part.

Please contact us if you have any questions about either parts of the research. Our contact details are below.

Who can participate?
The criteria are described below.

You can take part in this study if you are:

- An adult aged 50+
- Have a diagnosis or think you are autistic (self-identify)
- Are currently a resident in the UK
- Have either no learning disability or a mild learning disability

If you are aged under 50 then you are unfortunately unable to take part in this study.

If you would like to speak with someone from the research team please contact Amy or Hassan:

amy.gillions.20@ucl.ac.uk
hasssan.mansour.17@ucl.ac.uk

For more information or to take part in the study please follow this link or scan the QR code:
https://uclpsych.eu.qualtrics.com/jfe/form/SV_0NXnwWFZdrr1lwa

This study is funded by University College London (UCL) and was granted ethical approval by the Research Ethics Committee. Division of Psychology and Language Sciences - Ethical Approval Number: 22117/001

Appendix 11: Participant information sheet for the qualitative interviews

RESEARCH DEPARTMENT OF CLINICAL,
EDUCATIONAL AND HEALTH PSYCHOLOGY

UCL

Autism and Ageing Research Project – Interview Information Sheet for Autistic Participants

UCL Research Ethics Committee Approval ID Number: 22117/001

Study Title: Understanding the Healthcare Needs of Autistic Adults aged 50 or over (Interview Study)

Department: UCL Division of Psychology and Language Sciences

Research Team and Contact Details: Amy Gillions and Hassan Mansour (Trainee Clinical Psychologists), amy.gillions.20@ucl.ac.uk and hassan.mansour.17@ucl.ac.uk

Research Supervisors: Dr Joshua Stott and Dr Liz O'Nions

UCL Data Protection Officer: Alexandra Potts

You are being invited to take part in a research project. Before you decide whether to take part, please read through this information sheet to find out what taking part will involve. If you have any questions, please contact the research team using the information above.

Project overview
In the United Kingdom, very little is known about the healthcare needs of autistic adults aged 50 or over and their experiences getting help with physical and mental health problems from the NHS or other services.

The aim of this study is to find out more about the healthcare needs of autistic people aged 50 or over. The research aims to explore things that help or hinder people in accessing healthcare. We hope that our findings will show how services can better meet the needs of autistic people aged 50 or over.

Who can be involved in the project?
We are inviting autistic adults aged 50 or over and their carers to take part. We welcome autistic people who have a formal diagnosis and those who think they are autistic (self-identify). We also want to recruit people with a learning disability and autism. You can take part by yourself or with some help from a friend, partner, supporter, or carer.

What will happen if I choose to participate and what does taking part involve?
If you choose to take part in the Interview Study, Amy or Hassan will contact you to arrange a convenient time to talk to you. If you have a preference for a male or female interviewer, please let us know. We will ask you a few questions and listen to your experiences of using the NHS and any other healthcare services.

We will talk to you over a video call platform like Zoom/Microsoft Teams or on the telephone for between an hour and 90 minutes, or less if you would prefer. You can pause the session at any time if you need a break or split it over a couple of days. If you would like a supporter to be with you during the call, that is fine with us.

We will be asking you about your experiences of accessing healthcare support and the impact of ageing onto this. Our conversation will be recorded using a secure voice recorder which we can then listen to and write down exactly what you tell us. All interview texts and recordings will be kept confidential and will only be accessible to the research team or in some instances to a private transcription company called Scrintal. This is compliant with the latest data and privacy rules. We will transcribe recordings within 3-months of the interview and will delete the audio recordings within 1-week after they have been transcribed. When we write up our results, we will leave out any details that could identify you.

If you would rather talk about some of your experiences but not others, that is fine – it is completely up to you what you tell us. If you would like to stop the interview at any time, or if you change your mind about taking part, just let us know. You also have up to 1-month after you have completed the interview to withdraw your responses from the study.

Are there any possible risks to taking part?
You may find that talking about your healthcare experiences makes you feel emotional. Should you experience any distress at any point, we will pause the interview and check if you would like to continue or offer you a break. We have consulted autistic people who have helped us design our questions to ensure they are appropriate.

Are there any possible benefits to taking part?
As a thank you for your time we will provide you with a £15 voucher. Whilst there are no immediate benefits to taking part in the project, we hope that our findings will help us to better understand the healthcare needs of autistic adults aged 50 or over and their experiences of using healthcare services. We can also offer signposting and suggestions for additional support during the interview.

How will interview recordings be stored?
Interview recordings will be transferred from the voice recording device to a secure computer drive to be stored. The recordings will only be used by the research team. Once the recordings have been transcribed, they will be erased.

What will happen to the findings?
The data collected will be written up for the purposes of two doctorate research projects completed by Amy and Hassan (research team). Following this, we also hope to publish the results in a research journal. We aim to finish the project by September 2023.

Summary
This project aims to better understand the healthcare needs and experiences accessing healthcare services for autistic adults aged 50 or over. We want to interview autistic adults aged 50 or over to collect in-depth information about their health.

It is entirely up to you whether you decide to take part. You can keep this information sheet to refer back to and you will also be asked to complete a consent form. You can withdraw from the project at any time.

If you have any questions that are not addressed in this information sheet, please contact the research team before completing the consent form. Our contact details are at the top of this page.

Privacy notice
The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk. This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice. The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices. The lawful basis that will be used to process your personal data are: 'Public task' for personal data and' Research purposes' for special category data. Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible. If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at data-protection@ucl.ac.uk.

Appendix 12: Consent form for the qualitative interviews

RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL AND HEALTH PSYCHOLOGY

UCL

Consent Form (Qualitative Interview)

Title of Study: Understanding the views of autistic people aged 50 or over on their healthcare needs
Department: UCL Division of Psychology and Language Sciences
Contact Details of Researcher(s): amy.gillions.20@ucl.ac.uk and hassan.mansour.17@ucl.ac.uk
Contact Details of Principal Researcher: j.stott@ucl.ac.uk
UCL Ethical Approval ID Number: 22117/001

Please complete this form after you have read the Information Sheet or listened to an explanation about the research.

If you have any questions, then please ask the researcher before you decide whether to join in.

Before agreeing to be interviewed about your experiences, please read the following statements and tick which boxes you agree with:

		Tick Box
1.	I confirm that I have read and understood the information sheet.	
2.	I consent to participate in this study voluntarily and understand that I can terminate the interview and at any time without giving a reason.	
3.	I understand that I can choose to withdraw my responses for up to 1-month after taking part in the interview.	
4.	I understand that my personal information will be used for the purposes explained to me and will be stored securely following data protection laws.	
5.	I understand that the interview will be recorded and transcribed by the research team or a private transcription company.	
6.	I understand that the interview recording and transcript will be stored securely and confidentially. The recording will be deleted within 1 week after it has been transcribed.	

7.	I understand the potential benefits and risks of participating and the support that will be available to me should I become distressed during the course of the interview.	
8.	I understand that the information I provide during the interview may be combined with that of other participants and published as a report. No details that could identify me will be included in the report.	
9.	I would like to receive a summary of the published report when it is available.	
10.	I confirm that I understand the inclusion criteria as detailed in the Information Sheet and explained to me by the researcher.	
11.	I confirm that I am aged 50 or above and I can confirm that I have been diagnosed autistic or identify as autistic.	
12.	I am aware of the contact details of the research team if I have any concerns about the study.	

_____ _____ _____

Name of participant Date Signature

Appendix 13a: Participant general characteristics

ID	Country	Age	Gender	Sexual Orientation	Ethnicity	Relationship Status	Education Level	Autism	Age of diagnosis	Intellectual Disability	Living situation	Employment
1	England	72	Female	Asexual	White British	Single	Postgraduate	Formal diagnosis	61-70	No	Alone	Self-employed
2	England	75	Male	Heterosexual	White British	Widower	Undergraduate	Self-identify	71-80	No	Alone	Retired
3	England	70	Female	Other	White British	Single	Postgraduate	Formal diagnosis	61-70	No	Alone	Retired
4	England	72	Female	Heterosexual	Any other White	Divorced	School up to age 18	Formal diagnosis	51-60	No	Alone	Retired
5	Scotland	67	Male	Heterosexual	Any other White	Married	Undergraduate	Formal diagnosis	61-70	No	With spouse	Retired
6	England	71	Female	Heterosexual	White British	Widowed	Undergraduate	Formal diagnosis	61-70	No	Alone	Retired, Volunteer
7	England	69	Female	Heterosexual	White British	Married	Undergraduate	Formal diagnosis	61-70	No	With spouse	Retired
8	England	65	Male	Heterosexual	White British	Married	School up to age 16	Formal diagnosis	61-70	Self-identify	With spouse	Employed (part-time)
9	Scotland	72	Female	Heterosexual	White British	Separated	Undergraduate	Formal diagnosis	61-70	No	Alone	Retired
10	England	65	Non-binary	Other	White British	Married	Postgraduate	Self-identify	51-60	No	With partner	Retired, Volunteer
11	England	65	Male	Heterosexual	White British	Married	Did not complete	Formal diagnosis	61-70	Yes (Mild)	With spouse	Self-employed
12	England	70	Male	Heterosexual	White British	Married	Postgraduate	Formal diagnosis	51-60	Yes (Mild)	With spouse	Retired
13	England	65	Other	Heterosexual	White British	Married	Doctorate	Formal diagnosis	61-70	No	With spouse	Retired
14	Scotland	75	Male	Prefer not to say	White British	Married	Undergraduate	Formal diagnosis	61-70	Self-identify	With spouse	Retired
15	England	65	Male	Heterosexual	White British	Single	Undergraduate	Formal diagnosis	51-60	No	Alone	Retired
16	England	65	Female	Heterosexual	White British	Divorced	Undergraduate	Formal diagnosis	61-70	No	Alone	Employed (part-time)
17	England	67	Male	Heterosexual	White British	Married	Undergraduate	Formal diagnosis	51-60	Self-identify	Alone	Retired
18	England	68	Male	Heterosexual	White British	Married	Doctorate	Formal diagnosis	21-30	No	With spouse	Retired
19	England	66	Non-binary	Homosexual	White British	Single	Doctorate	Formal diagnosis	0-10	No	Alone	Employed (part-time)
20	England	68	Male	Heterosexual	Asian British	Married	School up to age 16	Self-identify	N/A	Yes (Moderate)	With spouse	N/A

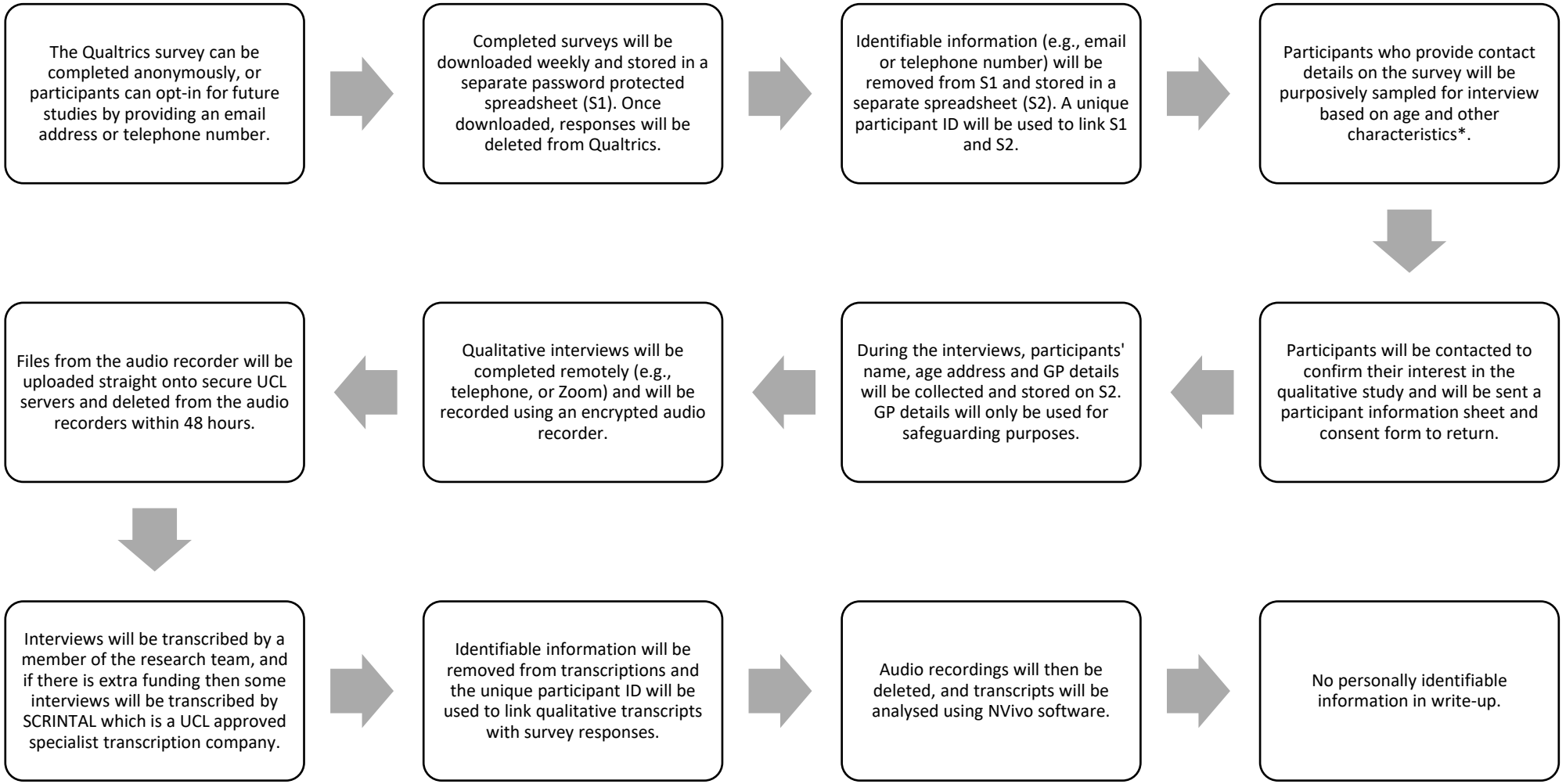
Appendix 13b: Participant physical and mental health difficulties

ID	Country	Age	Gender	Have you or the person you care for ever experienced any physical health difficulties?	Have you or the person you care for ever experienced any mental health difficulties?	In general, how would you describe your/their current physical health	In general, how would you describe your/their current mental health	Have you/they had any difficulties when accessing healthcare services?
1	England	72	Female	Yes	Yes	Average	Average	Yes
2	England	75	Male	Yes	Yes	Poor	Poor	Yes
3	England	70	Female	Yes	No	Average	Poor	Yes
4	England	72	Female	Yes	No	Average	Average	Yes
5	Scotland	67	Male	Yes	Yes	Very Good	Good	Yes
6	England	71	Female	Yes	Yes	Poor	Average	Yes
7	England	69	Female	Yes	Yes	Good	Good	Yes
8	England	65	Male	Yes	Yes	Very Good	Very Good	No
9	Scotland	72	Female	Yes	Yes	Poor	Poor	Yes
10	England	65	Non-binary	Yes	Yes	Average	Very Good	Yes
11	England	65	Male	No	Yes	Good	Very Poor	Yes
12	England	70	Male	Yes	Yes	Poor	Average	Yes
13	England	65	Other	Yes	No	Average	Very Good	No
14	Scotland	75	Male	Yes	Yes	Poor	Very Poor	Yes
15	England	65	Male	Yes	Yes	Poor	Average	Yes
16	England	65	Female	Yes	Yes	Good	Average	Yes
17	England	67	Male	Yes	Yes	Poor	Poor	No
18	England	68	Male	Yes	Yes	Poor	Poor	Yes
19	England	66	Non-binary	Yes	Yes	Poor	Average	Yes
20	England	68	Male	Yes	Yes	Very Poor	Very Poor	Yes

Appendix 14: Experts by experience committee recommendations

Generic Changes Across Resources
• We changed our wording from intellectual disability to learning disability. We understand that while academic fields are moving towards the term intellectual disability, learning disability is preferred amongst service users. • We have made language simpler.
Changes to the Poster
• There was a preference for the green-coloured posters, so we chose this one. • We added images to make the poster more visual. • We simplified some of the language (e.g., changing 'participants' to 'people'). • Some of the larger paragraphs have been split into shorter sentences. • We have tried to clarify that there are two separate parts of the research that you can take part in. • We have increased font size to make it clearer and easier to read.
Changes to Consent Forms and PIS
• Language has been simplified. • Sentences have been shortened. • We have changed participate to take part.
Changes to the Online Survey
• We have added self-employed as an option to the employment section. • We have shortened some questions and added an option to save progress. • There is a bar at the top of the page which shows people how far they are through the survey.
Changes to the Interview Questions
• We have included specific prompts we would ask people, especially about their experiences accessing support from their GP. • We will ensure we clarify with participants what we mean by the breadth of healthcare experiences with relevant prompts. • We have added some explicit questions that people suggested (e.g. how do different parts of your identity or life influence your healthcare needs).

Appendix 15: Data protection procedure



**Where target populations such as carers of individuals with intellectual disabilities cannot be purposively recruited through the surveys, snowball sampling methods may be used to recruit this population. Their data will be stored in the same way once obtained (e.g., name and email address in S2) and the same data flow methods will be used.*

Appendix 16: Interview topic guide

Healthcare needs:

- What are your current healthcare needs?
    - Do you have a diagnosis for any physical or mental health difficulties?
        - If yes, then how easy was it to access support?
    - Do you have any current concerns about your healthcare needs?
- What have been your healthcare needs been in the past?
    - Have you received a diagnosis for a condition which you felt was inaccurate?

Access to services:

- How often do you access healthcare services?
    - What helps when trying to access, or engage with healthcare services?
    - What is it like contacting your GP?
    - Have you been to hospital in the last few years?
        - If yes, what was this experience like?
- How do you experience services which offer healthcare support to you?
    - How do you feel you are treated?
    - Do you feel like they listen or understand?
    - Do you feel respected?
- How have your healthcare needs changed, particularly as you have gotten older?
    - How do you think your experience of services or accessing services compares now to how it was when you were younger?

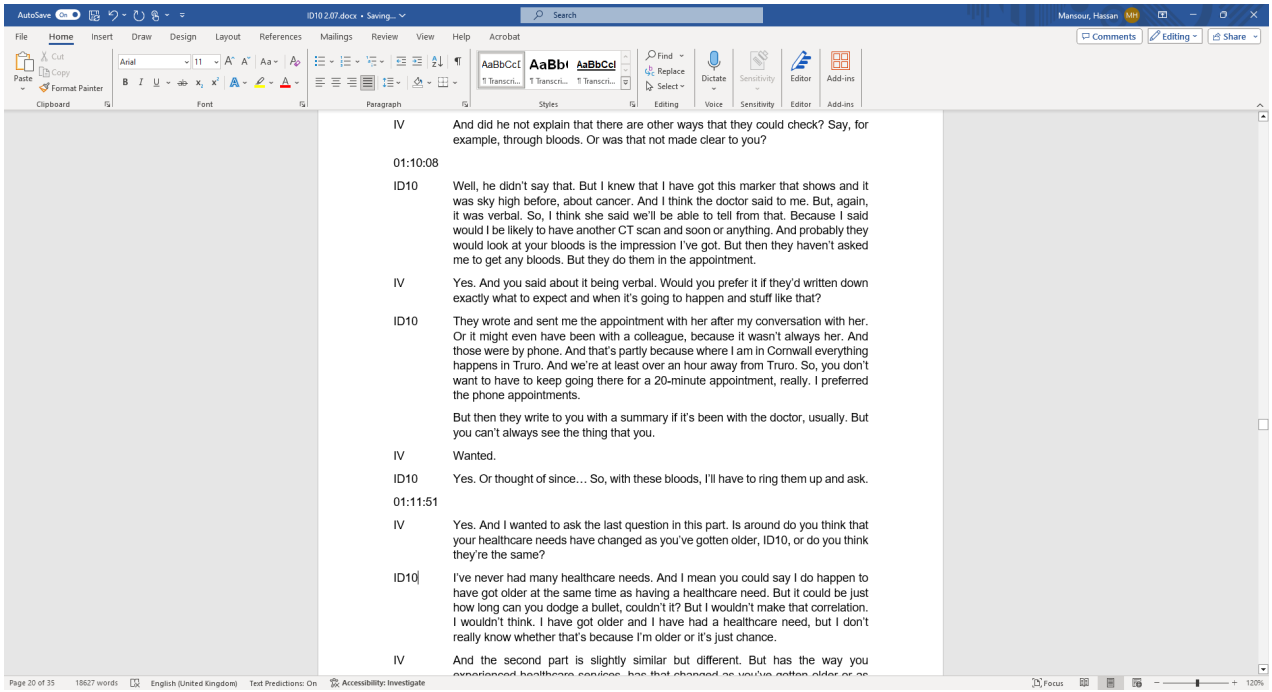
Facilitators, and barriers to healthcare services:

- Have you experienced any difficulties when accessing or engaging with services?
    - What are the barriers which prevent you from accessing healthcare services?
    - What has helped you overcome these barriers?
- How do other aspects of your identity/life influence your healthcare needs and access to services?
    - Ethnicity, religion, gender, sexuality, socioeconomic status, and spirituality
    - Wider social network including family, friends, and support groups
- How have services tried to adapt to meet your needs?
    - What helps facilitate access to healthcare services, particularly in older age?
    - Prompts: communication and literacy, explaining things in different ways
- What impact has COVID and the pandemic had on your experiences with healthcare services?

Summing up:

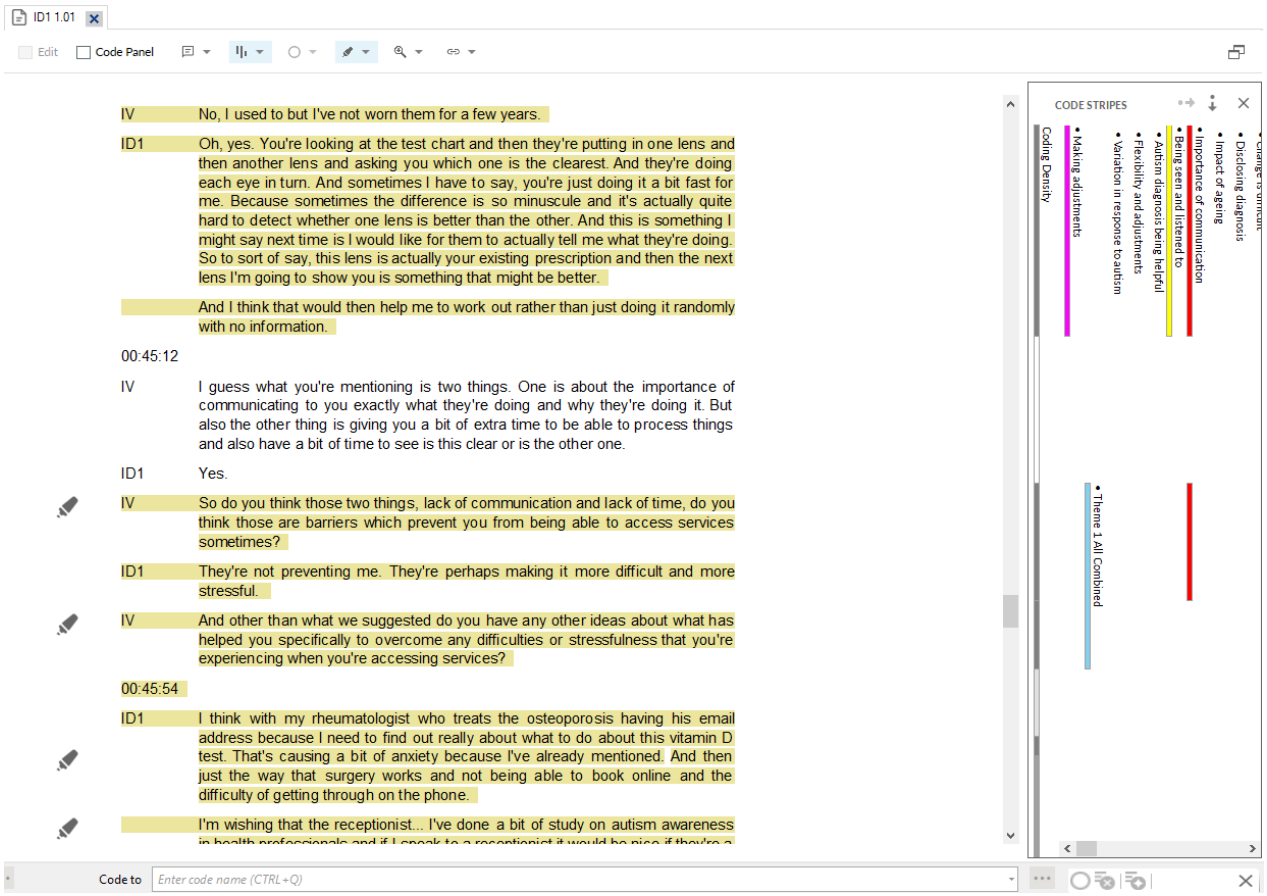
- How could healthcare services be improved for older autistic people?

Appendix 17: Transcript extract



IV	And did he not explain that there are other ways that they could check? Say, for example, through bloods. Or was that not made clear to you?
01:10:08	
ID10	Well, he didn't say that. But I knew that I have got this marker that shows and it was sky high before, about cancer. And I think the doctor said to me. But, again, it was verbal. So, I think she said we'll be able to tell from that. Because I said would I be likely to have another CT scan and soon or anything. And probably they would look at your bloods is the impression I've got. But then they haven't asked me to get any bloods. But they do them in the appointment.
IV	Yes. And you said about it being verbal. Would you prefer it if they'd written down exactly what to expect and when it's going to happen and stuff like that?
ID10	They wrote and sent me the appointment with her after my conversation with her. Or it might even have been with a colleague, because it wasn't always her. And those were by phone. And that's partly because where I am in Cornwall everything happens in Truro. And we're at least over an hour away from Truro. So, you don't want to have to keep going there for a 20-minute appointment, really. I preferred the phone appointments. But then they write to you with a summary if it's been with the doctor, usually. But you can't always see the thing that you.
IV	Wanted.
ID10	Yes. Or thought of since… So, with these bloods, I'll have to ring them up and ask.
01:11:51	
IV	Yes. And I wanted to ask the last question in this part. Is around do you think that your healthcare needs have changed as you've gotten older, ID10, or do you think they're the same?
ID10	I've never had many healthcare needs. And I mean you could say I do happen to have got older at the same time as having a healthcare need. But it could be just how long can you dodge a bullet, couldn't it? But I wouldn't make that correlation. I wouldn't think. I have got older and I have had a healthcare need, but I don't really know whether that's because I'm older or it's just chance.
IV	And the second part is slightly similar but different. But has the way you

Appendix 18: Coded transcript



IV	No, I used to but I've not worn them for a few years.
ID1	Oh, yes. You're looking at the test chart and then they're putting in one lens and then another lens and asking you which one is the clearest. And they're doing each eye in turn. And sometimes I have to say, you're just doing it a bit fast for me. Because sometimes the difference is so minuscule and it's actually quite hard to detect whether one lens is better than the other. And this is something I might say next time is I would like for them to actually tell me what they're doing. So to sort of say, this lens is actually your existing prescription and then the next lens I'm going to show you is something that might be better.
	And I think that would then help me to work out rather than just doing it randomly with no information.
00:45:12	
IV	I guess what you're mentioning is two things. One is about the importance of communicating to you exactly what they're doing and why they're doing it. But also the other thing is giving you a bit of extra time to be able to process things and also have a bit of time to see is this clear or is the other one.
ID1	Yes.
IV	So do you think those two things, lack of communication and lack of time, do you think those are barriers which prevent you from being able to access services sometimes?
ID1	They're not preventing me. They're perhaps making it more difficult and more stressful.
IV	And other than what we suggested do you have any other ideas about what has helped you specifically to overcome any difficulties or stressfulness that you're experiencing when you're accessing services?
00:45:54	
ID1	I think with my rheumatologist who treats the osteoporosis having his email address because I need to find out really about what to do about this vitamin D test. That's causing a bit of anxiety because I've already mentioned. And then just the way that surgery works and not being able to book online and the difficulty of getting through on the phone.
	I'm wishing that the receptionist... I've done a bit of study on autism awareness

Appendix 19: Coding framework

Codes

Name	Files	References	Created by	Created on	Modified by	Modified on
Accumilation of past trauma	11	24	HM	07/04/2023 19:18	HM	15/04/2023 20:25
Acknoweldging the autism in therapy	3	3	HM	07/04/2023 19:18	HM	06/04/2023 16:18
Adapting self to navigate services	6	11	HM	07/04/2023 19:18	HM	13/04/2023 21:35
Adapting to healthcare	4	9	HM	07/04/2023 19:18	HM	05/04/2023 20:46
ADD REF	15	57	HM	08/07/2023 12:09	HM	08/07/2023 12:43
Ageing and autism	6	11	HM	07/04/2023 19:18	HM	14/04/2023 13:17
Alexithymia	2	4	HM	07/04/2023 19:18	HM	08/03/2023 15:05
Allergy or sensitivity	6	6	HM	07/04/2023 19:18	HM	02/06/2023 09:10
Always had good physical health	5	11	HM	07/04/2023 19:18	HM	08/04/2023 21:35
Ambulance or paramedics	3	6	HM	07/04/2023 19:18	HM	08/04/2023 22:09
Anxiety	16	55	HM	07/04/2023 19:18	HM	13/07/2023 14:05
Appointment or procedure serving a purpose	5	10	HM	07/04/2023 19:18	HM	14/04/2023 21:56
Asking for help is hard	5	7	HM	07/04/2023 19:18	HM	14/04/2023 22:01
Autism assessment	10	14	HM	07/04/2023 19:18	HM	08/04/2023 21:41
Autism diagnosis being helpful	18	48	HM	07/04/2023 19:18	HM	13/07/2023 14:19
Autism interacts	2	5	HM	07/04/2023 19:18	HM	02/06/2023 09:11
Autism presenting differently in females	4	6	HM	07/04/2023 19:18	HM	13/04/2023 18:50
Autism presents differently for everyone	12	21	HM	07/04/2023 19:18	HM	13/04/2023 20:49
Autism seen as learning disability	8	14	HM	13/07/2023 14:10	HM	13/07/2023 14:11
Autism training	10	18	HM	07/04/2023 19:18	HM	08/04/2023 22:16
Automated texts or emails	8	10	HM	07/04/2023 19:18	HM	13/04/2023 21:47
Bad experiences with healthcare services	8	23	HM	07/04/2023 19:18	HM	15/04/2023 21:02
Becoming more isolated	14	35	HM	07/04/2023 19:18	HM	15/04/2023 19:58
Begining and end being important	5	7	HM	07/04/2023 19:18	HM	14/04/2023 12:15

HM 239 Items

Appendix 20: Developing themes