Doctoral Thesis

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Personality Disorder and Late Diagnosis of Autism Spectrum Condition in Secondary Mental Health Services

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Section	Main Text	Appendices, References, Figures, and Tables	Total
Abstract	261	-	261
Literature Review	7982	7982	15,964
Empirical Paper	7998	9817	17,815
Critical Appraisal	3694	887	4581
Ethics Section	3835	7548	11,383
Total	23,770	26,234	50,004

Thesis Abstract

This thesis is comprised of four sections including a systematic literature review, an empirical paper, a critical appraisal, and an ethics section. The systematic literature review is a thematic synthesis of 18 papers exploring the impact of autism spectrum condition and attention deficit hyperactivity disorder in adulthood on mental health and wellbeing. Three themes were generated: (1) Beliefs about diagnoses impact adults' experiences of being diagnosed, (2) Diagnosis inspires new perspectives on relationships with self and others, and (3) Diagnosis provides a new lens for the past and the future. Clinical implications to support mitigating the negative impact of adult diagnosis on mental health and wellbeing are discussed, alongside implications for future research. The empirical research paper explores the lived experience of secondary mental health services from the perspective of autistic adults who were diagnosed with a personality disorder prior to their diagnosis of autism spectrum condition. Six participants engaged in semi-structured interviews which were analysed using Interpretive Phenomenological Analysis. The analysis generated four themes: (1) Realising the nuances of having a diagnosis and having a diagnostic label, (2) "A steep learning curve": seeking understanding amongst misconceptions, (3) Having a voice in secondary mental health services: a dichotomy of control and helplessness, and (4) Compassion cultivates compassion: service and individual level disparities in care. Clinical implications for secondary mental health services are explored alongside implications for future research. The critical appraisal expands on the clinical and r3esearch implications for both papers, alongside the strengths and limitations of the papers, and critical reflections on the papers and the research process.

Declaration

This thesis presents research completed in partial fulfilment of the Doctorate in Clinical Psychology at Lancaster University, submitted in June 2024. The work presented within this thesis is the author's own work and has not been submitted for any other academic award. The work does not contain the work of any other authors, except for where due reference is made.

Name: Jade Dalton

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Contents

Section One: Systematic Literature Review

The impact of being diagnosed with Autism or ADHD as an adult on mental health and wellbeing: a systematic review and thematic synthesis

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Abstract

Purpose: Rates of adult diagnosis of autism spectrum condition (ASC) and attention deficit hyperactivity disorder (ADHD) are increasing in the UK, and adults diagnosed with ASC or ADHD are more likely to experience difficulties with their mental health. This thematic synthesis of the current qualitative literature aimed to explore the impact on mental health and wellbeing of being diagnosed with ASC or ADHD in adulthood.

Method: A systematic search was conducted across four scientific databases. 18 papers met the inclusion criteria to be included in the review and were analysed using thematic synthesis to generate analytic themes across the papers.

Results: The synthesis generated three analytical themes: (1) Beliefs about diagnoses impact adults' experiences of being diagnosed, (2) Diagnosis inspires new perspectives on relationships with self and others, (3) Diagnosis provides a new lens for the past and the future. A conceptualization of the negative impacts on mental health and wellbeing of adult ASC or ADHD diagnosis, alongside the protective factors that mitigate this impact, was developed based on these themes.

Conclusion: The findings highlight the post-diagnostic support needs of those diagnosed with ASC or ADHD in adulthood. Strategies to mitigate the impact of adult diagnosis are suggested. Further research is needed to better understand the impact of receiving a neurodevelopmental diagnosis.

Keywords: Autism, ADHD, mental health, wellbeing, adult diagnosis

Autism spectrum condition (ASC) and attention deficit hyperactivity disorder (ADHD) are neurodevelopmental conditions defined within the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) (American Psychiatric Association, 2013) as conditions with onset during the developmental period, producing deficits that impair functioning. ASC will be used as the preferred terminology throughout in line with the movement away from negative, deficit-based language such as ‘disorder’ (Baron-Cohen, 2000; Kenny et al., 2016). Whilst ASC and ADHD have historically been understood as childhood conditions (Fleischmann & Miller, 2013; Howlin, 2021) increased incidences of adults being diagnosed with ASC (Russell et al., 2022) and ADHD (McKechnie et al., 2023) have been recognised in the United Kingdom.

Diagnostic trends for ASC within the UK between 1998 – 2018 show the highest increases in rates of ASC diagnosis were for individuals aged 19 and over (Russell et al., 2022). Changes in the DSM-5 (APA, 2013) criteria for ASC have been acknowledged as the first clearly established recognition of the identification of ASC in adults (Lai & BaronCohen, 2015), and the new diagnostic criteria are applicable to all ages, improving access to diagnosis in adulthood.

A similar pattern has emerged for ADHD, with the highest relative increase in incidence rates of ADHD diagnosis in the UK between 2000 – 2018 being within the adult population (McKechnie et al., 2023). The recognition of childhood symptoms of ADHD persisting into adulthood within ADHD research has led to changes in the DSM-5, acknowledging the lifelong nature of the condition (Lovett & Harrison, 2021). Furthermore, the number of criteria required to be met for an ADHD diagnosis has been reduced for adults, considering the common decline in associated difficulties with age (Thapar et al., 2017).

However, adult-onset ADHD is not recognised as a distinct diagnosis despite research suggesting that up to 90% of adults diagnosed with ADHD do not have a childhood diagnosis (Moffitt et al., 2015).

Despite recent increases in diagnostic rates across ASC and ADHD in adulthood, missed diagnosis and misdiagnoses are common. Autistic adults are frequently misdiagnosed with psychiatric diagnoses such as personality disorders and mood disorders prior to their ASC diagnosis (Fusar-Poli et al., 2022; Gesi et al., 2021), and professionals' lack of knowledge about ASC presentations has been cited as a contributing factor to misdiagnosis (Bargiela et al., 2016; Lupindo et al., 2023). Similarly, adults diagnosed with ADHD commonly experience difficulties associated with psychiatric diagnoses such as anxiety and personality disorders (Weisler & Goodman, 2008) which may mask ADHD symptoms (Culpepper & Mattingly, 2010) leading to missed diagnosis. Furthermore, ADHD symptoms may be misunderstood by professionals as psychiatric diagnoses (Ginsberg et al., 2014), with some professionals reporting that diagnosing ADHD in adulthood is challenging and uncomfortable (Adler et al., 2009). It has been suggested that on initial presentation to psychiatric services, neurodevelopmental disorders are often not considered or investigated by mental health professionals (Eberhard et al., 2022).

Whilst misdiagnosis can present as a barrier to adult ASC and ADHD diagnosis, psychiatric diagnoses can also present as comorbidities within the two groups. A higher prevalence of mental health difficulties for adults with ASC and ADHD compared to the general population is acknowledged within the literature, with approximately a third of autistic adults experiencing symptoms of mental ill-health (NHS England, 2023) and up to 80% of adults with ADHD presenting with psychiatric comorbidities (Klassen et al., 2010).

Suicidal ideation is also more common across the two groups, with up to 66% of autistic adults (Curnow et al., 2023) and 46% of adults with ADHD (Giupponi et al., 2020) reporting experiences of suicidality.

Given the high comorbidity rates between ASC, ADHD, and mental health difficulties, alongside ASC and ADHD being commonly misdiagnosed as psychiatric disorders in adults, high rates of contact with mental health services are expected. Within the UK, the number of autistic people admitted to psychiatric inpatient units rose by 7.3% between March 2017 and August 2023 (NHS England, 2023). There is currently a paucity of information surrounding mental health service use and ADHD, however one study identified that 38.7% of an adult psychiatric inpatient sample had a diagnosis of ADHD or met the diagnostic criteria (Lines & Sadek, 2018).

Recommendations for interventions for comorbid mental health difficulties in adults with ASC have been made by the National Institute for Health and Care Excellence (NICE, 2021). Whilst no specific interventions are suggested as best practice, recommendations are made for adapting NICE recommended interventions for the specific comorbid disorder. Receiving care through existing pathways has been linked to poor outcomes for adults with ASC (Maloret & Scott, 2018) despite these recommendations. Autistic adults continue to experience mental health services as being designed around neurotypical norms, and report not benefitting from accessing them (Crane et al., 2019).

Current ADHD guidelines recommend treatment of ADHD that considers the potential impact of any mental health comorbidities (NICE, 2019; Royal College of Psychiatrists, 2023) but do not detail any adaptations that should be considered for existing mental health interventions. Additionally, a lack of non-pharmacological interventions for adults with ADHD has been reported, alongside barriers related to engagement and accessibility when they are available (Matheson et al., 2013).

This evidence highlights that despite a known increase in adult diagnoses of ASC and ADHD, alongside significantly more adults with ASC and ADHD experiencing mental health difficulties, adult mental health services are currently not meeting the needs of these populations. Therefore, it may be important to understand the impact that receiving a diagnosis of ASC or ADHD as an adult has on mental health and wellbeing. This may further the understanding of the potential difficulties individuals diagnosed with ASC and ADHD in adulthood may experience, and that they may subsequently seek support for through mental health services. The clinical implications of this understanding may help guide the improvement of mental health service provision for these two groups by highlighting the possible pathways that may need adapting for neurodivergent adults.

Recent quantitative findings revealed receiving a neurodevelopmental diagnosis may improve self-esteem and wellbeing over time (Corden et al., 2021) and lack of post-diagnostic support may negatively impact mental health and wellbeing (Jones et al., 2014). Therefore, the current systematic review aims to synthesise qualitative findings from the current literature to explore and understand the impact of diagnosis of ASC and ADHD in adulthood in relation to mental health and wellbeing. The review will address the question: what is the impact of being diagnosed with Autism or ADHD as an adult on mental health and wellbeing?

Method

Design

A systematic review was conducted using the thematic synthesis framework described by Thomas and Harden (2008). Thematic synthesis allowed the qualitative data within the studies to be translated into analytical themes that went beyond the original findings to address the review question. Thematic synthesis was selected as the most appropriate approach over meta-ethnography given the balance of descriptive and phenomenological approaches used within the studies. Thematic synthesis was designed to synthesize descriptive data that relates to the experiences and perspectives of participants (Thomas & Harden, 2008).

Search Strategy

A protocol for the systematic review was registered on PROSPERO (CRD42024504262). Search terms were developed based on the review question which was developed using the PICO format (Richardson et al., 1995): population, intervention, comparison, outcome. Three key concepts were highlighted within the review question, and an initial scoping search was conducted to develop a comprehensive list of keywords, subject headings, and medical subject headings (MeSH) relevant to each concept (Table 1). Search terms were combined using Boolean operators (Table 2) within the following databases: PsychInfo, PubMed, CINAHL, and SCOPUS.

Inclusion and Exclusion Criteria

The review included only peer-reviewed papers to help ensure research that is methodologically high quality was used within the review. Studies that gathered qualitative data exploring participants' experiences of being diagnosed with ASC or ADHD were included, including mixed-methods studies. Only papers written in English, or with an English language translation, were included.

The National Health Service definition of wellbeing (NHS England, 2022) and the Department of Health definition of mental health (DoH, 2011) were used to inform the development of the searches, alongside concepts measured within the Warwick Edinburgh Mental Well-Being Scale (WEMWBS) (Tennant et al., 2007). Based on these definitions, research that explored participants' experiences relating to positive affect, psychological functioning, interpersonal relationships and connection to others, and safety and coping was included.

Search terms pertaining to age of participants were not included as all databases allowed for results to be filtered by age of participants; all searches were filtered by adult age (18 years and over). Papers that included a combination of participants diagnosed in childhood (0-17 years) and participants diagnosed as adults (18 years and over) were included if it was explicit which lines of data pertained to which age range. Papers which included parents' or carers' experiences alongside individuals' personal experiences of receiving an ASC or ADHD diagnosis were included if it was made explicit within the papers which lines of data pertained to each group.

Many of the papers within the review explored experiences outside of being diagnosed with ASC or ADHD such as pre-diagnosis experiences. Papers that contained at least one distinct theme related to receiving a diagnosis, or that asked one question specific to the experience of receiving a diagnosis, were included within the review.

Search Results

The final search was conducted in January 2024 and has been outlined following the PRISMA guidelines (Moher et al., 2009) (Figure 1). The search yielded an initial total of 4036 papers. Rayyan software was used to support the screening of the papers, and 3942 papers' titles and abstracts were screened following the removal of duplicates. This process was then replicated for 10% of the papers by a second reviewer to reduce the risk of biased screening and human error (McDonagh et al., 2013). No conflicts were identified within this phase. This initial screening process yielded a total of 41 papers which were sought for retrieval; one paper was requested via the author however was not retrieved. A final screening process applying the inclusion and exclusion criteria resulted in 16 papers to be included in the review. A final search was conducted within the references of the final sample of papers and Google Scholar to ensure no relevant literature had been missed within the searches; two further papers were identified bringing the total number of papers used within the review to 18.

Quality Appraisal

The Critical Appraisal Skills Programme (CASP, 2018) checklist was used in the quality appraisal of the 18 papers included in the review (Table 4). The CASP was chosen due to its consideration to the robustness of sampling and reflexivity, which were important to consider in line with inclusion criteria and analysis of second order findings. The 10-point checklist was used alongside the scoring system introduced by Duggleby et al. (2010) which rates each paper as weak, moderate, or strong for providing evidence for each criterion (Table 3). Whilst scores were not used to exclude papers from the review, they have been considered in line with the strengths and limitations of the papers and the review itself.

Study Characteristics

Study characteristics can be found in Table 5. In summary, the 18 studies employed qualitative methodology as either the whole or part of the methodology. Interviews and analyses of existing online data were carried out across the studies, and results were analysed using qualitative analysis methods, primarily interpretive phenomenological analysis and thematic analysis. Much of the research was conducted using UK samples, with various other locations across the remaining studies.

Data Analysis

The qualitative findings within the papers that explored participants' experiences of receiving an ASC or ADHD diagnosis in relation to their mental health and wellbeing was analysed using the three steps of thematic synthesis outlined by Thomas and Harden (2008). Once the relevant parts of the results sections were identified using the inclusion and exclusion criteria, including first order constructs (participant's accounts of the impact on their mental health and wellbeing) and second order constructs (the authors' views and interpretations) which were analysed in conjunction, line by line coding was completed. This step involved coding each line of the data by applying a code generated by the author that captured the meaning and content of the data. These codes were then grouped based on similarities to develop descriptive themes capturing congruity in meaning. Finally, these descriptive themes were considered in relation to the review question, and analytical themes were developed which went beyond the original data and determined the key messages across the studies. Descriptive themes were shared with the research supervisor and analytical themes that were appropriately abstract to explain the descriptive themes were developed through supportive discussions. Appendix 1 provides a sample of this analysis process.

[INSERT FIGURE 1 HERE]

Results

Theme 1: Beliefs about diagnoses impact adults' experiences of being diagnosed.

Across 17 studies, representing research on ASC and ADHD, this theme highlights how beliefs about neurodevelopmental conditions can influence the impact of receiving a diagnosis in adulthood. Participants often had an awareness of the diagnoses and the stigma that surrounded them before they were diagnosed. For some adults with ADHD this stigma was internalized (Aoki et al., 2020b; Halleröd et al., 2015; Morgan, 2023). This self-stigma presented as an aversion to the label itself for some: "I don't say I have ADHD, I say that I have dyslexia, ADHD sounds so ugly in everyday speech" (Halleröd et al., 2015, p.7). For others, it highlighted their own ableist views: "I couldn't cope with it because of my own internalized ableism" (Morgan, 2023, p.7). One adult with ADHD described how they developed feelings of shame following diagnosis, "…you might not be respected for who you are and your thoughts and opinions are not valued as highly as before" (Halleröd et al., 2015, p.7). Feelings of disgust were also experienced by adults diagnosed with ADHD, with one participant linking their self-disgust to their own stigma towards the diagnosis: "…and felt disgusted that I was also one of those oddballs." (Aoki et al., 2020, p.4).

The perceived limitations of having a diagnosis meant that for some a sense of dread prevailed (Atherton et al., 2022; Halleröd et al., 2015; Powell & Acker, 2016; Wilson et al., 2023). This was linked to expectations of having a diagnosis that had been internalised based on the opinions of others: "…then you believe it yourself and then you live based on that …" (Halleröd et al., 2015, p.9). The sense that others perceived their new diagnosis as limiting was also described by autistic adults: "It limits the expectations of others, who watch me more closely, or assume I will never be able to do things at work or socially that I think I can do" (Powell & Acker, 2016, p.77).

Some autistic adults expressed worries about the stigma surrounding ASC. This included a fear that they would live up to the stigma, including being "complacent" or "making excuses" (Atherton et al., 2022), or that others would judge them based on the stigma (Powell & Acker, 2016). For some this led to feelings of frustration and anger, with one autistic adult feeling “angry that I’m the one in a hundred” (Powell & Acker, 2016, p.75).

In contrast, some autistic adults and adults with ADHD believed that diagnosis freed them from stigma associated with some of the ways they presented (Aoki et al., 2020b; Hansson Halleröd et al., 2015; Lewis, 2016; Powell & Acker, 2016; Wilson et al., 2023), with diagnostic labels replacing derogatory labels. One adult with ADHD explained “I’d rather be stamped with the ADHD label than walk around and have people think I’m weird” (Halleröd et al., 2015, p.6) and one autistic adult felt able to reframe her autistic traits as strengths: “I also understand that some of the personality traits which others led me to believe were faults or failings are not so, and may be applied in ways which render them as assets” (Lewis, 2016, p.350).

Having a diagnostic label as a new name for their challenges gave autistic adults the opportunity to embrace their new diagnosis as a strength (Atherton et al., 2022; Leedham et al., 2020; Lewis, 2016; Lupindo et al., 2022; Powell & Acker, 2016; Punshon et al., 2009; Wilson et al., 2023). Feelings of being stronger and more independent due to the diagnosis were explored by some: “…makes me feel glad, and stronger, and independent” (Powell & Acker, 2016, p.75) which had positive impacts on their wellbeing including providing a sense of relief and hope: “I felt very relieved that I'm hopeful, finally somebody has told me, actually, I'm suffering from a condition that I could do nothing about” (Lupindo et al., 2022, p.12).

Some adults with ADHD also viewed their differences as strengths following diagnosis (Aoki et al., 2020b; Fleischmann & Fleischmann, 2012; Halleröd et al., 2015). This included identifying that having an ADHD diagnosis had added something positive to their lives: “If I could choose a life without ADHD, I wouldn’t choose it, I would like to have it…

you get to have a pretty fun life…" (Halleröd et al., 2015, p.4). Mirroring the experiences of some of the autistic adults, the realisation of a diagnosis as a strength helped relieve difficult feelings for adults with ADHD: "A weight has been lifted from my shoulders!" (Fleischmann & Fleischmann, 2012, p.1491).

Across studies investigating ASC and ADHD the empowerment that came with receiving a diagnosis in adulthood was poignant (Atherton et al., 2022; Finch et al., 2022; Fleischmann & Fleischmann, 2012; Halleröd et al., 2015; Harmens et al., 2022; Leedham et al., 2020; Lewis, 2016; Powell & Acker, 2016). Being able to name their experiences was a powerful realisation, helping some participants to let go of the feeling that something was "wrong" with them, "The relief and empowerment I felt when I was diagnosed and finally discovered what 'was wrong with me' were overwhelming." (Harmens et al., 2022, p.46). One autistic adult highlighted that this feeling of empowerment was facilitated by the age of diagnosis: "I know that I'm a grown woman and I know who I am now. So, it's more powerful." (Leedham et al., 2020, p.142).

This theme highlights the impact of negative perceptions and stigma on mental health and wellbeing when diagnosed in adulthood. For some, the impact on their mental health and wellbeing was negative, experiencing shame, anger, and disgust. For others, having a diagnosis was viewed as a strength, particularly when it freed them from other labels associated with their challenges. This highlights the power that labels can have over mental health and wellbeing.

Theme 2: Diagnosis inspires new perspectives on relationships with self and others.

Within all 18 of the studies, being diagnosed in adulthood was described as pivotal in defining how the participants related to themselves and others. Both autistic adults and adults with ADHD reported a paradigm shift in how they viewed themselves post-diagnosis. For some, this was experienced as a new-found acceptance of themselves in light of having a diagnosis to explain their experiences (Fleischmann & Fleischmann, 2012; Halleröd et al., 2015; Lewis, 2016; Lupindo et al., 2022; Powell & Acker, 2016; Seers & Hogg, 2023; Wilson et al., 2023; Young et al., 2008). Alongside self-acceptance came freedom from trying to change things about themselves that they previously did not understand: "I get to accept those things about myself that I cannot really change" (Fleischmann & Fleischmann, 2012, p.1491). For others, accepting themselves as an autistic adult or an adult with ADHD meant that they no longer felt pressure to fit in with a neurotypical society: "I realized…a desire to embrace parts of myself that I had squelched over the years in order to 'fit in' and blend with society that was unforgiving and judgmental about differences" (Lewis, 2016, p.350).

For autistic adults this was particularly meaningful as it allowed them to stop masking, a common experience amongst autistic individuals which can lead to poor mental health and loss of identity (Bradley et al., 2021). One autistic adult described this as allowing them to stop being someone they're not: "…it's like you're wearing a mask, or you play a character around people. But I've kind of stopped trying to do that." (Lupindo et al., 2022. p.12). Adults with ADHD also experienced a realization that it was okay for them to be their authentic selves following diagnosis: "I have ADHD, I might not manage this because that's what everyone around me and my psychologists are saying and it's OK for me to be weird, I get to say strange stuff…" (Hallerod et al., 2015, p.9).

For some, their new identity was more challenging to accept. The new diagnostic labels threatened some participants' sense of individuality (Halleröd et al., 2015; Lewis, 2016) whilst some rejected the idea of a new identity altogether: "…that damn word doesn't make me, me" (Leedham et al., 2020, p.141). Autistic adults who experienced challenges with their new identity described continuing to mask as a consequence (Atherton et al., 2022;

Leedham et al., 2020; Lewis, 2016) and feeling an increased pressure to change themselves: “I feel like my life now revolves around trying to change the things that for 30 years I’ve just accepted as being part of me” (Lewis, 2016, p.350). Others experienced uncertainty around who they were and how much of their identity was defined by ASC or ADHD. One adult with ADHD described this as wondering “who am I really?” (Aoki et al., 2020a). Feelings of uncertainty associated with perceived changes in identity led many autistic adults and adults with ADHD to feel anger, sadness, anxiety, and frustration (Aoki et al., 2020a; Halleröd et al., 2015; Lewis, 2016; Stagg & Belcher, 2019).

Participants within the studies also described how their relationships with others changed. For some, these changes were beneficial to their mental health and wellbeing through the increased understanding of their experiences by others (Atherton et al., 2022; Halleröd et al., 2015; Leedham et al., 2020; Lupindo et al., 2022; Morgan, 2023; Powell & Acker, 2016; Young et al., 2008). Some experienced receiving a diagnosis as increasing understanding through legitimizing their experiences to others, as explained by one autistic adult:

> It was a bit like if you don't have a diagnosis or something, it kind of feels like they're out to get to you. Instead of trying to be positive, they're like, ‘Why aren't you doing this?’ And now there's less of that… so I would say it’s less stressful. (Atherton et al., 2022, p.3647).

Increased understanding from others was described by autistic adults and adults with ADHD as a salient factor in enabling themselves and others to understand why past difficulties in relationships had transpired. For some, this helped strengthen these relationships through greater mutual understanding: “It’s really improved our relationship because he’s realised now that a lot of the arguments we had were me misunderstanding what he’d said and him misunderstanding how I'd reacted." (Leedham et al., 2020, p.140). For others, gaining a new label or identity in adulthood presented challenges associated with maintaining relationships with others, as this was met with scepticism: "My dad doesn't believe my ADHD diagnosis" (Morgan, 2023, p.7).

Whilst some participants experienced acceptance and understanding from others, many described the reaction from those around them as unhelpful. For some, this presented as a distinct change in how those closest to them responded to parts of them that were newly described by the diagnostic label of autism or ADHD, as described by one autistic adult: "Close relatives, wife, mother, daughter have become more focused on coping with me" (Powell & Acker, 2016, p.77). As one adult with ADHD explained, the diagnostic labels could create a new perspective of them in the minds of others, a lens which they did not necessarily want to be viewed through: "I don't want them to judge me any different, I want them to know me just for me without a label." (Young et al., 2008, p.498). These reactions created worry for some regarding how possible future relationships may be affected, including professional relationships: "I know a lot of jobs and businesses; they wouldn't hire you if they find out that you are on the spectrum" (Lupindo et al., 2022, p.24193).

Lived experience of challenging responses from others, alongside anxieties about future reactions, made the decision to disclose their new diagnoses challenging for many participants. This was linked to increased experiences of stress and anxiety, and participants described choosing not to disclose their diagnosis: "I kind of fear that people will see me differently if I start to bring it up and that they might have to act in a certain way when they're dealing with me. So, I try and avoid that" (Lupindo et al., 2022, p.24193). Reluctance to disclose was linked to potential negative repercussions, including worries about how the diagnosis may affect their professional or romantic lives: "…if I meet a guy, how do I tell him about this?" (Hallerod et al., 2015, p.9).

One feature of disclosure that was described exclusively by the autistic adults within the studies was its role in fostering new connections, finding a new community of autistic adults they could connect with, increasing their social networks: "'It's a way to get like a social life... where I have never really had one" (Punshon et al., 2009, p.277). These new connections helped autistic adults feel a sense of connection and belonging and furthered their newly developed understanding of themselves: "I'm in quite a few groups with autistic women which has helped a lot to know who I am." (Seers & Hogg, 2023, p.35).

This theme presents the experiences of self-acceptance and acceptance from others, which can positively or negatively impact relationships and in turn, wellbeing. For those who accepted their new diagnosis, wellbeing improved through increased understanding and reduced masking, whilst those who experienced the diagnoses as a threat to their identity hid their diagnosis and experienced difficult emotions. Furthermore, negative responses from others further reinforced continued masking and non-disclosure, whilst accepting responses facilitated improved relationships through increased understanding.

Theme 3: Diagnosis provides a new lens for the past and the future.

Each of the 18 studies explored participants' experiences of re-evaluating their past and future following diagnosis of ADHD or ASC in adulthood. Many participants had spent most of their lives searching for an explanation for their challenges and experiencing difficulties that they struggled to understand. Both autistic adults and adults with ADHD diagnosed in adulthood described diagnosis as the key to understanding their difficult past experiences. This brought a sense of relief and joy to some, as one adult with ADHD explained: “In one part of me I felt elated. It was almost like, ‘Oh there’s an actual reason why I acted like that’” (Young et al., 2008, p.496).

A new label of ADHD or ASC provided, for some, a realisation that past diagnoses were incorrect. Disassociating themselves from these diagnoses, often of mental health conditions, was experienced as “A relief, because for years and years everything has been put down to anxiety and depression” (Stagg et al., 2019, p.353). This allowed participants to rewrite their pasts through the new lens provided to them by their new, accurate, diagnosis which provided instant improvements to the wellbeing of some: “It was almost like things got better just from knowing that it was ADHD” (Halleröd et al., 2015, p.8). However, it also highlighted past healthcare failings and missed opportunities for earlier diagnosis, which had a negative impact on the wellbeing of many autistic adults and adults with ADHD.

Diagnosis of ASC or ADHD in adulthood was viewed by many of the participants as a late diagnosis, one that was missed by those around them including school, family, and healthcare professionals: “And there’s these glaring issues and you see how multiple times you were failed by various professionals that should have and could have seen issues” (Atherton et al., 2022, p.3648). This cultivated difficult emotions including anger (Halleröd et al., 2015; Leedham et al., 2020), frustration (Ghanouni & Seaker, 2023; Lupindo et al., 2022), and sadness (Leedham et al., 2020; Morgan, 2023). These difficult emotions were attributed to missed opportunities and experiences in their lives that the participants believed could have been avoided with timely diagnosis. One participant described how their life may have looked different had they been diagnosed in childhood: “Imagine if someone had figured out ten years ago that I had ADHD, then I’d have been spared all of this, wouldn’t have had to go to jail, maybe I’d have had a real job” (Hallerod et al., 2015, p.10). For others, late diagnosis highlighted missed opportunities for support that may have improved their experiences in childhood. As one autistic adult explained, this brought feelings of sadness with the realisation of their ASC diagnosis in adulthood: “Saddened, too, for all the lost opportunities that would likely have come about had I known and received intervention and loving understanding as a child” (Lewis, 2016, p.351).

Some studies described how participants were often left to face these challenging experiences alone due to a lack of adult ASC and ADHD service provision (Hickey et al., 2018; Lewis, 2016; Lupindo et al., 2022; Morgan, 2023; Powell & Acker, 2016; Stagg & Belcher, 2019; Young et al., 2008). One adult with ADHD explained how the lack of support for adults with ADHD furthered the detrimental effects diagnosis had on their wellbeing: “It is so painful, I am finding it hard to cope with, there are 42 years of pain that I must deal with, and no support” (Morgan, 2023, p.8). Likewise, autistic adults found themselves dealing with the negative impact of diagnosis without support. One autistic adult described this as: “…having to, psychologically, on your own, reassess your whole life” (Hickey et al., 2018).

Whilst many participants within the studies experienced a lack of post-diagnostic emotional support, many also experienced diagnosis as a gateway to accessing support and adaptations that were not available to them previously. One autistic adult described ASC as a “signpost” rather than a label (Atherton et al., 2022, p.3647). Having a diagnosis that increased access to support gave participants a new perspective on their futures, one with more hope. For some, this was experienced as increasing access to services that afforded them tangible benefits including financial support: “It helped me get help from social services” (Powell & Acker, 2016, p.77). For others, parts of their lives that were previously challenging were improved through access to adaptations: “My work colleagues also know about it so we've now built-in measures to accommodate for my needs" (Lupindo et al., 2022, p.24193).

However, despite having a diagnosis of ASC or ADHD, accessing support was still challenging for many. Participants described having little to no knowledge about their new diagnosis: "I did not know anything about ADHD" (Aokie et al., 2020, p.4). Furthermore, participants described the professionals involved in their care as also being ill-informed.: "The psychiatrist acknowledged that he had little or no knowledge of the subject" (Powell & Acker, 2016, p.77). For the autistic adults within the studies, barriers to support were described as support for autistic adults not being readily available: "It's almost impossible to find professional help as an adult" (Lewis, 2016, p.351). This experience also translated from the participants' healthcare into their personal lives, where they identified adaptations or support would improve their wellbeing: "I still failed at work, I still failed because the world isn't set up for me…not having supports and accommodations, it just broke me." (Ghanouni et al., 2023, p.6). Accounts of autistic adults within the studies identifying a need for mental health support following diagnosis suggest that, even when they had access to relevant professionals, this was not always helpful: "I did have a consultant psychiatrist, and the one time when I was really bad, around Christmas time, I contacted him and he never got back to me" (Stagg et al., 2019, p.355). Similarly, whilst adults diagnosed with ADHD within the studies found medication was readily accessible, support for their mental health and wellbeing following diagnosis was not so accessible: "I was just offered medication and that was it, no support." (Morgan, 2023, p.8). These experiences left participants feeling uncertain (Finch et al., 2022; Powell & Acker, 2016; Young et al., 2008) or even hopeless about the future (Lewis, 2016), overwhelmed by how to move forwards (Leedham et al., 2020; Lewis, 2016; Powell & Acker, 2016).

This final theme reflects how diagnosis in adulthood can facilitate hope for the future through access to support and adaptations, alongside grief and frustration that this was not available for them previously due to their diagnosis being missed. In contrast, post-diagnostic support was not available for many, negatively affecting their mental health and wellbeing.

Discussion

This systematic review aimed to synthesize existing literature to explore the impact of adult diagnosis of ASC or ADHD on mental health and wellbeing. A systematic search of the literature produced 18 papers that were selected as appropriate for inclusion within the review. Thematic synthesis of the results within these papers resulted in three themes: (1) Beliefs about diagnoses impact adults' experiences of being diagnosed, (2) Diagnosis inspires new perspectives on relationships with self and others, (3) Diagnosis provides a new lens for the past and the future. By exploring these themes, novel hypotheses and concepts addressing the review aims will be discussed below, alongside clinical and research implications, and limitations of the review.

The stigma towards ASC and ADHD was often internalised by participants across the reviewed literature, affecting their mental health and wellbeing following diagnosis, including experiences of shame, dread, and being unable to cope. Research outside of the scope of the present review has identified that stigma and negative attitudes are commonly experienced by autistic adults (Botha et al., 2022; Cage et al., 2019) and adults with ADHD (Lebowitz, 2016; Masuch et al., 2019). For autistic adults, stigma towards ASC can lead to social isolation (Nevill & White, 2011), dehumanization (Cage et al., 2019), and increased masking (Davidson & Henderson, 2010). Adults with ADHD experience consequences of stigma from others such as reduced self-esteem (Masuch et al., 2019) and social rejection (Paulson et al., 2005). These experienced consequences of stigma towards ASC and ADHD are associated with negative impacts on mental health and wellbeing (Mueller et al., 2012; Perry et al., 2022). Furthermore, experiences of stigma can present as a barrier to helpseeking within both populations, including mental health support (Malik-Soni et al., 2022; Vogan et al., 2017; Wright et al., 2015). This may be experienced by those diagnosed with ASC or ADHD in adulthood as a vicious cycle of stigma leading to poor mental health and wellbeing and feeling unable to access appropriate services, adaptations, or interventions, negatively impacting mental health and wellbeing.

Beliefs about diagnoses and labels also mitigated negative effects of adult diagnosis on mental health and wellbeing. Having a label of ASC or ADHD was beneficial to some, as their experiences of stigma had stemmed from characteristics they previously did not have an explanation for, leading to labels such as “lazy” and “freak” (Halleröd et al., 2015; Wilson et al., 2023). Debates around diagnostic labels are ongoing (Hoff et al., 2020) with arguments suggesting that developmental disorder diagnoses may be harmful (Werkhoven et al., 2022). This review suggests that the impact of receiving a neurodevelopmental diagnosis in adulthood is an individual experience rather than diagnosis being universally helpful or unhelpful. Additionally, the positive impact of diagnosis due to increased self-understanding highlights the importance of professionals having a good understanding of the diagnoses to enable effective joint understanding with newly diagnosed adults. Research exploring the experiences of professionals has highlighted that mental health professionals have reported a lack of knowledge and competence when working with ASC (Maddox et al., 2020) and ADHD (French et al., 2019).

Adults across the reviewed studies experienced changes in their relationship with themselves and others post-diagnosis. Improved understanding and acceptance of themselves helped autistic adults and adults with ADHD to stop striving for change related to fitting into neurotypical norms. ASC and ADHD identities may be conceptualized as social identities (Tajfel & Turner, 1979) as they combine individual characteristics with characteristics that they share with a group. Existing literature suggests that autistic adults and adults with ADHD often identify as belonging to a group associated with their diagnosis (Cooper et al., 2017; Young et al., 2019). Belonging to a group is associated with improved wellbeing including improved mood and self-esteem (Greenaway et al., 2016), although this was an experience shared only by autistic adults within the reviewed studies.

Being diagnosed in adulthood was experienced as a threat to some participants' individuality, leading some to reject or hide their new diagnosis and face difficult emotional experiences. Existing literature suggests that those diagnosed with ASC later in life experience more difficulties associated with their new identity (Johnson & Joshi, 2016). Similarly, diagnosis in young adulthood rather than childhood has been associated with more difficulties accepting an association with the identity of having ADHD (Jones & Hesse, 2018). Given all participants within the reviewed studies were diagnosed as adults, age appears to be an important factor in mediating identity-threat following ASC and ADHD diagnosis. This supports the existing literature that argues for more timely ASC and ADHD diagnosis (Fernell et al., 2013; Long & Coats, 2022) which may mitigate the impact on mental health and wellbeing associated with identity difficulties.

An individual's mental health and wellbeing can be affected by their relationships (Santini et al., 2015) and relationships are impacted by the individual's mental health and wellbeing (Seligman, 2011). Within the reviewed studies, autistic adults and adults with ADHD described varying impacts of adult diagnosis on their relationships. Negative impacts of diagnosis were described for familial, romantic, and professional relationships, leading some participants to avoid disclosing their new diagnosis to others, alongside increased stress and anxiety associated with the potential consequences of others finding out about the diagnoses. Not disclosing diagnoses was described as mitigating possible negative reactions from others, an outcome that has been reported by autistic individuals (Thompson-Hodgetts et al., 2020) and adults with ADHD (Toner et al., 2006) within the existing literature.

Finally, the reviewed studies explored how ASC or ADHD diagnosis in adulthood provided a new lens through which the past and the future could be viewed. For some, this inspired hope for the future through improved access to support and adaptations, alongside forgiveness and understanding towards their past selves. Others felt angry, frustrated, and sad at the realization that their diagnosis had been missed for so long. Routes to neurodevelopmental diagnosis via the NHS often have long waiting times (Russell et al., 2022; Smith et al., 2024), and it may be that delays associated with waiting times rather than age of diagnosis alone are contributing factors to negative impacts on mental health and wellbeing. Furthermore, difficulties accessing support perpetuated the negative impact on mental health and wellbeing of participants, who reported feelings of hopelessness, uncertainty, and overwhelm regarding their futures. Whilst it is encouraging that diagnosis improved access to services for autistic adults and adults with ADHD post-diagnosis, these services are not keeping up with the increasing demand within the UK (Crane et al., 2018; Smith et al., 2024).

A conceptualization of the negative impacts on mental health and wellbeing of adult ASC or ADHD diagnosis, alongside the protective factors that mitigate this impact, was developed based on the themes explored within the review (Fig. 2). The negative impacts are characterised as internalized stigma, identity threat, and regret and hopelessness. Stigma from others, non-disclosure, and lack of support are represented as contributing factors towards these negative impacts, alongside the bi-directional effects of these negative impacts on maintaining some of the contributing factors. Finally, protective factors that have been discussed within the reviewed studies against the negative impact on mental health and wellbeing, or that improved mental health and wellbeing following diagnosis, are listed. The figure was developed to highlight the ways that services who may support those diagnosed in adulthood might help to mitigate negative impacts of diagnosis on mental health and wellbeing.

[INSERT FIGURE 2 HERE]

Clinical Implications

The results of this review highlight the negative impacts of adult diagnosis of ASC or ADHD on mental health and wellbeing. Contributing and protective factors have also been highlighted, which inform important clinical implications for services supporting individuals diagnosed with ASC or ADHD in adulthood.

Stigma associated with ASC and ADHD is a contributing factor to the negative impacts of internalised stigma and identity threat within the present review, which was mitigated by positive opinions about diagnostic labels and increased understandings of the diagnoses. Research suggests that improving knowledge and awareness about a diagnosis improves attitudes (Mavropoulou & Sideridis, 2014), which is more effective than targeting reducing stigma (Gillespie-Lynch et al., 2015). Participants within the reviewed studies highlighted professionals' lack of knowledge about ASC and ADHD, with some having to find this information themselves. Increasing knowledge and awareness of the diagnoses within services that support adults post-diagnosis would be an important first step in tackling the negative impact of stigma. This knowledge could then be passed on to adults pre and post diagnosis, potentially mitigating the negative impact of internalised stigma and identity threat.

Secondly, challenges associated with disclosing a new diagnosis of ASC or ADHD may serve as a barrier to accessing protective resources such as post-diagnostic support, adaptations, and social groups. Whilst non-disclosure may aid autistic adults and adults with ADHD in belonging to neurotypical groups, this is often experienced as stressful (Joachim & Acorn, 2000) and requires the individual to mask, which can exacerbate mental health difficulties (Cage & Troxell-Whitman, 2019). Increasing access to support groups or social groups post-diagnosis may reduce the burden of disclosure as being given access to a group for neurodivergent individuals makes the presence of a diagnosis implicit and could mitigate feelings of hopelessness through a sense of belonging and access to support. In turn, an increased sense of belonging can mitigate identity threat (Slepian & Jacoby-Senghor, 2021), an identified barrier to disclosing diagnoses within the review.

Finally, many participants within the reviewed studies experienced feelings of anger and regret related to understanding their diagnosis as late or missed during childhood. There is a growing body of literature highlighting the benefits and risks of early diagnosis of ASC and ADHD (Brasher & Stapel-Wax, 2020; Long & Coats, 2022; Okoye et al., 2023) and recommendations have been made to improve ASC (Department of Health and Social Care, 2021) and ADHD (Asherson et al., 2022; Young et al., 2021) diagnostic and treatment services. However, for those who are not diagnosed until adulthood, support to process the impact of late diagnosis is important to address the associated negative impact on mental health and wellbeing. A recent investigation into the post-diagnostic support needs of autistic adults highlighted emotional and psychological support as a key priority to address the impact of late diagnosis (Crowson et al., 2024), and psychological support for adults diagnosed with ADHD has been found to be effective within one UK primary care trial (Asherson et al., 2022).

Limitations and Further Research

The present review investigated 18 studies that explored the experiences of individuals diagnosed with ASC or ADHD in adulthood. Of the 18 studies, only 5 represented adult ADHD diagnosis. This may limit the review's representation of the adult ADHD experience, and suggests further research is needed exploring the experience of adult ADHD diagnosis. In particular, research exploring the post-diagnostic support needs of adults with ADHD from a lived experience perspective, which has been explored with autistic adults (Crowson et al., 2024). This would be important further research as the perspectives of those with lived experience can be vital in identifying gaps and flaws within service provisions, and in recommending effective solutions (Sunkel & Sartor, 2022).

The influence of the author's own perspectives on the synthesis of the studies may be a limitation within the review. An example of this is the author's own experiences of working with adults who have received ASC or ADHD diagnoses in adulthood, and therefore their pre-existing understanding and assumptions regarding the impact on mental health and wellbeing. To mitigate this risk, the author ensured that the principle of reflexivity was adhered to throughout the process of synthesizing the qualitative data, reflecting on their own perspectives and motivations throughout (Yardley, 2000) (Appendix 2).

The review explored the experiences of being diagnosed in adulthood as late or delayed. However, given the lengthy waiting times for both ASC and ADHD diagnostic services including child services (ADHD UK, 2023; Royal College of Psychiatrists, 2023), it may be that individuals diagnosed during childhood or adolescence also experience their diagnosis as late or delayed, impacting their mental health and wellbeing. Research exploring the phenomenon of late or delayed neurodevelopmental diagnoses within these populations may be beneficial to explore clinical need outside of adult mental health services.

Furthermore, many of the papers within the screening stage of this review were excluded as they included individuals diagnosed before adulthood, and when individual participants were diagnosed was not made explicit within the results. This limits the review in excluding a proportion of the targeted population. A further review incorporating the experiences of autistic adults and adults with ADHD, excluding age of diagnosis criteria, may be valuable in exploring impact of diagnosis on mental health and wellbeing, and the life course.

Finally, given the growing waiting times for both ASC and ADHD diagnostic services (Morris, 2024), further research into the impact on mental health and wellbeing for adults waiting to access diagnostic assessment is recommended. Current literature primarily explores these experiences in the past for those diagnosed in adulthood. Research exploring the live impact of delayed diagnosis and waiting periods may be beneficial in informing preventative measures regarding the impact on mental health and wellbeing. Preventative mental health strategies have been found to be less stigmatizing and more accessible (Singh et al., 2022), which would be particularly beneficial to autistic adults and adults with ADHD, as highlighted by the present review.

Conclusion

The present review explored the impact of ASC and ADHD diagnosis in adulthood on mental health and wellbeing, revealing three key themes pertaining to perceptions of diagnoses, relationships with self and others, and perspectives of the past and future. The findings highlighted the needs of autistic adults and adults with ADHD in relation to postdiagnostic support, and strategies to mitigate the impact on mental health and wellbeing are suggested. Furthermore, a need for future research is explored to broaden the understanding of the impact of neurodevelopmental diagnoses and move towards measures to prevent the negative impact on mental health and wellbeing.

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Figure and Table Captions

Fig. 1 PRISMA flowchart

Fig. 2 Conceptualisation of the findings of the systematic review

Table 1 Key concepts, keywords, and subject headings

Table 2 Final search strategy

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Table 4 Scores and score descriptors for CASP ratings (Duggleby et al., 2010)

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Fig. 1

PRISMA flowchart

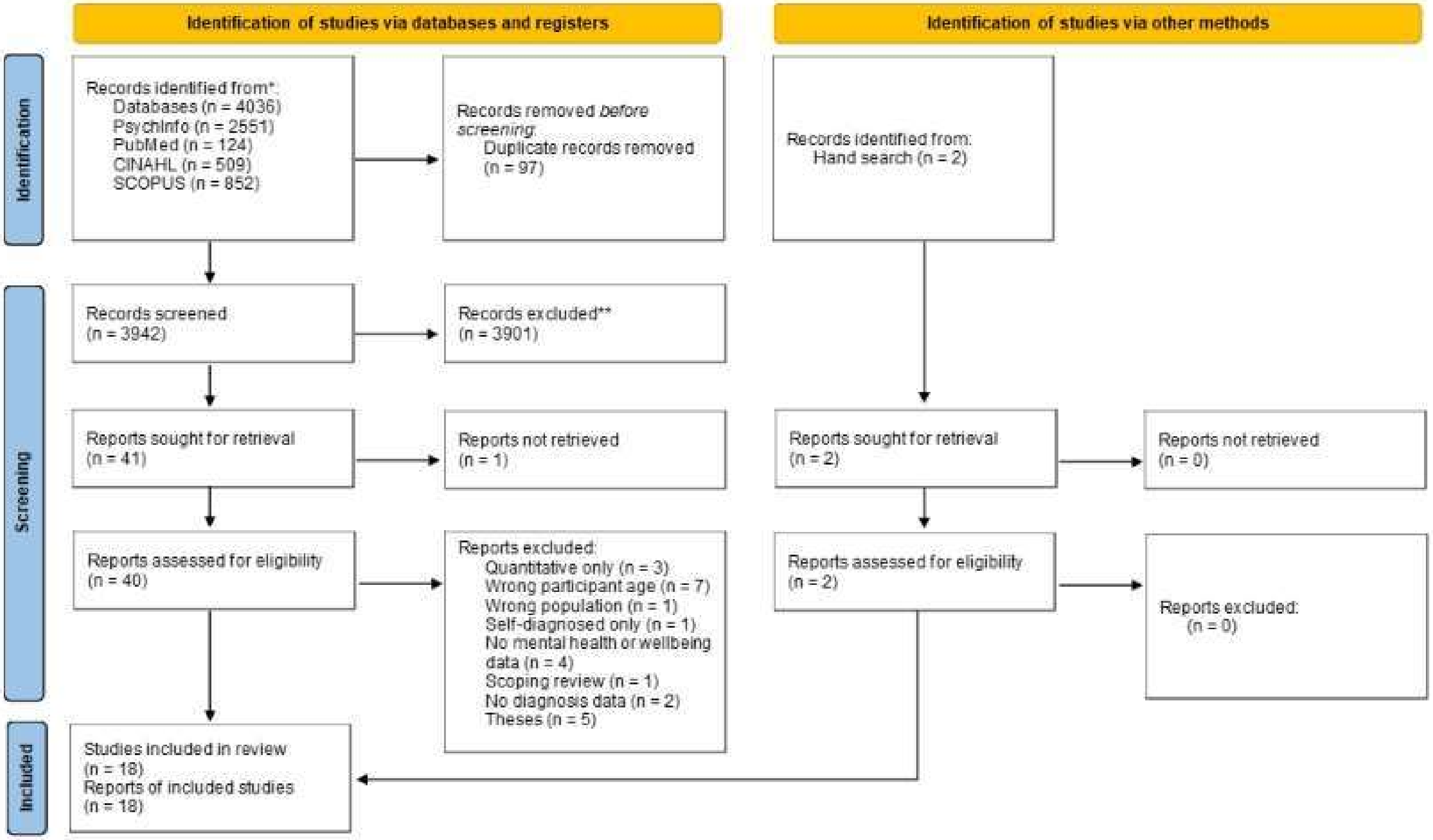

Fig. 2

Conceptualisation of the findings of the systematic review

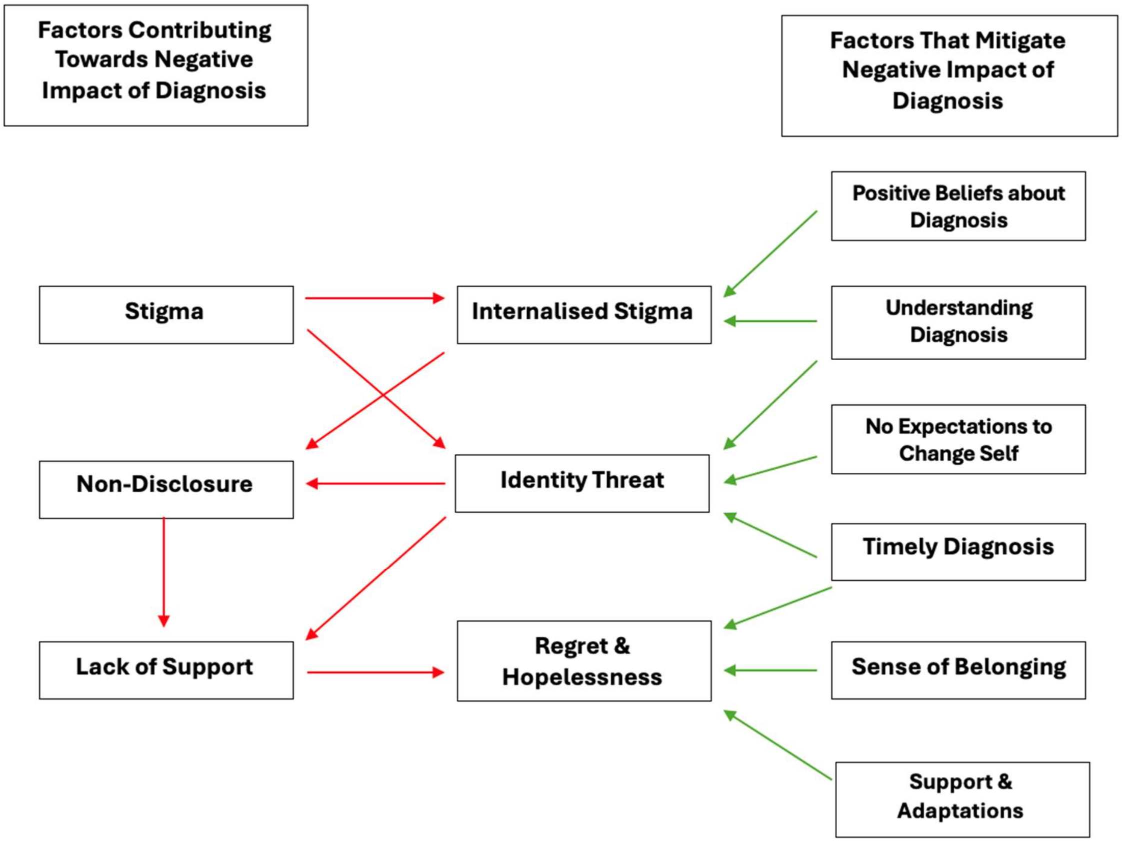

Table 1

Table of Key Concepts, Keywords, and Subject Headings

Concept	Keywords	Subject Headings e.g. MeSH
Concept 1 ASC/ADHD diagnosis	Attention deficit hyperactivity disorder ADHD Autism spectrum disorders Developmental disabilities Autism diagnosis ADHD diagnosis Autism spectrum conditions Asperger's Syndrome	Attention deficit hyperactivity disorder Autism Spectrum Disorders
Concept 2 Impact	Patient experiences Client attitudes Experiences ADHD Lived experiences Experiences	Life experiences Client attitudes Adult attitudes Narratives

Concept 3	Self perception	Stigma
Mental health and wellbeing	Wellbeing/Well being	Psychological Consequence
	Mental health	Mental Health
	Quality of life	Wellbeing/Well being
	Psychological wellbeing	Self-esteem
	Self-concept	Quality of life
		Consequence
		Narratives

Table 2

Final Search strategy

Key Concept	Search Terms (Boolean)
Key concept 1: ASC/ADHD diagnosis	TI (“Autis*” OR “ASD” OR “Autism Spectrum Disorder*” OR “ASC” OR “Autism Spectrum Condition*” OR “Autis* diagnos*” OR “Asperger*” OR “ADHD” OR “Attention Deficit Hyperactivity Disorder*” OR “Attention Deficit-Hyperactivity Disorder*” OR “ADHD Diagnos*” OR “Developmental disability*”) OR AB (“Autis*” OR “ASD” OR “Autism Spectrum Disorder*” OR “ASC” OR “Autism Spectrum Condition*” OR “Autis* diagnos*” OR “Asperger*” OR “ADHD” OR “Attention Deficit Hyperactivity Disorder*” OR “Attention Deficit-Hyperactivity Disorder*” OR “ADHD Diagnos*” OR “Developmental disability*”)
	AND
Key Concept 2: Impact	TI (“Experience*” OR “Perspective*” OR “View*” OR “Perception*” OR “Attitude*” OR “Lived experience*” OR “Life experience*” OR “Phenomenolog*” OR “Narrative*” OR “Consequence*” OR “Patient experience*” OR “Patient perspective*” OR “Patient attitude*” OR “Patient opinion*” OR “Patient perception*” OR “Patient feeling*”) OR

	AB (“Experience*” OR “Perspective*” OR “View*” OR “Perception*” OR “Attitude*” OR “Lived experience*” OR “Life experience*” OR “Phenomenolog*” OR “Narrative*” OR “Consequence*” OR “Patient experience*” OR “Patient perspective*” OR “Patient attitude*” OR “Patient opinion*” OR “Patient perception*” OR “Patient feeling*”)
	AND
Key Concept 3: Mental health and wellbeing	TI (“Wellbeing” OR “Well-being” OR “Well being” OR “Mental health” OR “Psychological well-being” OR “Psychological wellbeing” OR “Quality of life” OR “Wellness” OR “Psychological consequence*” OR “Self-concept” OR “Self-esteem”) OR AB (“Wellbeing” OR “Well-being” OR “Well being” OR “Mental health” OR “Psychological well-being” OR “Psychological wellbeing” OR “Quality of life” OR “Wellness” OR “Psychological consequence*” OR “Self-concept” OR “Self-esteem”)

Table 3

CASP Ratings of the 18 Studies Included in the Review

Author (Year)	Research Design	Sampling	Data Collection	Reflexivity	Ethical Issues	Data Analysis	Findings	Value	Total
Aoki et al. (2020)	2	2	3	1	1	2	3	2	16
Atherton et al. (2022)	3	2	3	1	1	2	3	3	18
Finch et al. (2022)	2	3	3	1	2	3	3	3	20
Fleischmann & Fleischmann (2012)	2	2	3	2	2	3	3	3	20
Ghanouni & Seaker (2023)	2	3	3	2	2	3	3	3	21
Halleröd et al. (2015)	3	3	3	2	1	3	3	3	21
Harmens et al. (2022)	2	2	3	2	2	2	2	3	18

Hickey et al. (2018)	2	3	3	2	1	2	3	2	18
Leedham et al. (2020)	2	2	2	2	1	2	3	3	17
Lewis (2016)	2	2	2	2	1	2	3	2	16
Lupindo et al. (2023)	2	3	3	3	2	3	3	3	22
Morgan (2023)	2	2	2	3	2	2	3	3	19
Powell & Acker (2016)	2	2	2	1	1	2	3	2	15
Punshon et al. (2009)	2	3	2	1	1	2	3	2	16
Seers & Hogg (2023)	3	2	2	2	1	2	3	2	17
Stagg & Belcher (2019)	3	2	2	2	1	3	3	3	19

Wilson	3	2	3	2	1	3	3	3	20
Young	2	2	3	1	1	2	3	2	16

Table 4

Scores and score descriptors for CASP ratings (Duggleby et al., 2010)

Score	Score Description
1	Weak – little to no justification and/or explanation of the issue addressed by the CASP question
2	Moderate – the issue is addressed but is not fully elaborated on or fully justified
3	Strong – the issue is addressed, justified, and explained extensively

Table 5

Summary of characteristics of the included studies

Author (Year)	ASC/ADHD	Research Aims	Methodology	Participants	Location
Aoki et al. (2020)	ADHD	To explore and understand the diagnosis-related experiences of adults diagnosed with ADHD.	Semi-structured interviews. Thematic analysis.	12 individuals aged 20 and over, diagnosed with ADHD in adulthood.	Japan
Atherton et al. (2022)	ASC	To explore identity, quality of life, and impact of late diagnosis in autistic adults.	Semi-structured interviews. Interpretive phenomenological analysis.	8 adults with ASC (4 male, 4 female) who received an ASC diagnosis over the age of 18.	UK
Finch et al. (2022)	ASC	To better understand the quality of life of autistic adults.	Interviews. Thematic analysis.	29 adults with ASC (16 male, 13 female) aged 20-71, 27 of whom received an ASC diagnosis as an adult.	UK
Fleischmann &	ADHD	To investigate how adults with ADHD view the course of their lives.	Analysis of existing online data. Grounded theory.	71 personal narratives of individuals diagnosed with ADHD as an adult.	Not reported

Fleischmann (2012)					
Ghanouni & Seaker (2023)	ASC	To investigate the lived experiences of individuals diagnosed with ASC during adulthood.	Semi-structured interviews. Access to Health framework.	13 individuals with ASC aged 27 - 53, diagnosed between the ages of 18 - 52.	Canada
Halleröd et al. (2015)	ADHD	To explore how adults perceive and experience being diagnosed with ADHD.	Interviews. Phenomenography.	21 individuals (10 male, 11 female) diagnosed with ADHD during the research period.	Sweden
Harmens et al. (2022)	ASC	To examine the experiences of autistic women in relation to mental health, wellbeing, and the role of diagnosis.	Analysis of existing online data (blogs). Thematic analysis.	20 blogs written by 23 women with ASC. 22 had a formal ASC diagnosis and 21 were diagnosed as adults.	UK, Australia, Canada, USA.
Hickey et al. (2018)	ASC	To explore the lived experience of autism in older adulthood and perceptions of diagnosis.	Semi-structured interviews. Thematic analysis.	13 individuals (10 male, 3 female) diagnosed with ASC as adults.	UK

Leedham et al. (2020)	ASC	To understand the lived experience of females who receive an ASC diagnosis in middle to late adulthood.	Semi-structured interviews. Interpretive phenomenological analysis.	11 females diagnosed with ASC at age 40 or over.	UK
Lewis (2016)	ASC	To explore the experience of receiving an ASC diagnosis in adulthood.	Online survey. Descriptive phenomenology.	77 individuals (40 males, 32 females, 4 other) who received an ASC diagnosis between the ages of 18 – 60.	Australia, Belgium, Canada, Finland, Ireland, The Netherlands, Norway, Scotland, Singapore, Sweden, UK, USA.
Lupindo et al. (2023)	ASC	To explore the impact of late diagnosis of ASC on males.	Interviews. Thematic analysis.	10 males over the age of 25, diagnosed with ASC at age 18 or over.	South Africa.

Morgan (2023)	ADHD	To document the lived experience of an ADHD diagnosis in adulthood.	Narrative interviews. Grounded theory.	52 females aged 19 - 56 diagnosed with ADHD as adults.	UK
Powell & Acker (2016)	ASC (Asperger Syndrome)	To explore experiences of AS diagnosis and how it affects individuals' lives.	Surveys. Thematic analysis.	74 adults diagnosed with AS at an adult diagnostic clinic.	Not reported
Punshon et al. (2009)	ASC (Asperger Syndrome)	To identify experiences of adults with AS related to their diagnosis and how services might help individuals adjust to diagnoses.	Semi- structured interviews. Interpretive phenomenological analysis.	10 individuals (7 male, 3 female) aged 22 – 45 diagnosed with AS between the ages of 21 – 44.	UK
Seers & Hogg (2023)	ASC	To understand the impact of cultural norms on women's construction of the self within the context of an ASC diagnosis.	Semi-structured interviews. Thematic analysis.	8 females aged 24 – 53 diagnosed with ASC between the ages of 23 – 53.	Australia

Stagg & Belcher (2019)	ASC				
Wilson et al. (2023)	ASC	To explore autistic women's experiences of diagnosis related to self-compassion.	Interviews. Interpretive phenomenological analysis.	11 females who were diagnosed with ASC as adults.	UK
Young et al. (2008)	ADHD	To evaluate the psychological impact of diagnosis of ADHD in adulthood, including perception of self and the future.	Semi-structured interviews. Interpretive phenomenological analysis.	8 individuals (4 male, 4 female) aged 21 – 50 diagnosed with ADHD as adults.	UK

Section One Appendices

Appendix 1 Example of stages of analysis for theme 1: “Beliefs about diagnoses impact adults’ experiences of being diagnosed”

Appendix 2 Excerpt of the reflective log

Appendix 3 Journal of Autism and Developmental Disorders manuscript submission guidelines

Appendix 1

Example of stages of analysis for theme 1: “Beliefs about diagnoses impact adults’ experiences of being diagnosed”

Key Quote	Initial Codes	Descriptive Themes	Analytical Themes
It could also be the result of stigmatization, in the sense of having a characteristic which makes a person differ from the norm in a certain context, resulting in devaluation: “I don’t say I have ADHD, I say that I have dyslexia, ADHD sounds so ugly in everyday speech”	Stigma towards diagnosis	The impact of stigma	Beliefs about diagnoses impact adults’ experiences of being diagnosed
Charlotte explained that her diagnosis of autism and ADHD “crossed the line and I couldn’t cope with it because of my own internalized ableism”.	Ableism		
Once they had been diagnosed with ADHD and realized that it was a developmental disorder, their latent stigmas started to emerge and reflect back as self-stigmas: “[People with developmental disorder] seem to be odd.”	Self-Stigma		
It was experienced as less disparaging to have ADHD than to be categorised as, for example, “a disruptive child”, “impolite”, or “non-chalant”.	Diagnosis reducing stigma		

Participants described learning to see the benefits of having ASD and to embrace their differences, as one said, "I also understand that some of the personality traits which others led me to believe were faults or failings are not so, and may be applied in ways which render them as assets"	Diagnosis is a strength		
Some positive traits were attributed to ADHD and perceived as resources, such as creativity, new thinking, passion, quickness and productivity: "I see ADHD as something positive, almost more positive than negative.	Diagnosis is positive	Impact of positive perceptions of being diagnosed	
More than anything, a diagnosis was empowering as it demystified their social differences, providing a logical, scientific explanation for their experiences.	Diagnosis is empowering		
The experience of increased value meant treating themselves kindly and not tolerating bad treatment from others: "I've probably become tougher, I think ... now I know why they can't get on my case ... I don't have to take any crap"	Diagnosis increases resilience		

Having ADHD was less harmful to identity than being characterized as “stupid”, “lazy”, “angry”, “bad tempered”, “aggressive”, or “crazy”	Diagnostic label is better than others		
Certain participants expressed negative feelings “shocked because I didn’t think I had it” and “anger than I’m the on in a hundred”.	Negative feelins towards being diagnosed	Impact of negative perceptions of diagnoses	
But also frustrations about what this might mean for their sense of identity and the potential for diagnosis to be limiting forced them to question themselves: “*... I thought ‘am I just anything other than these symptoms?’ Um, that really upset me ... I sort of started doubting my ability to do my job.”*	Diagnosis is limiting		
“[People with developmental disorder] seem to be odd. I was shocked and felt disgusted that I was also one of those oddballs.”	Disgust towards diagnosis		
“I disliked the word ‘developmental disorder’. It seemed to indicate lack of development and looking stupid.”	Dislike of diagnostic labels		
Many participants had negative attitudes and biased views toward developmental disorders.	Negative attitudes towards diagnoses		

Appendix 2

Excerpt of the Reflective Log

"Whilst analysing the papers within the review I was aware of the potential impact of my previous work experience, particularly working alongside women who were diagnosed with ASC or ADHD in adulthood. I am aware through my work and the development of by empirical research that there are gender differences in rates and timeliness of ASC and ADHD diagnosis. I noticed, particularly when anaylsing papers exploring the experiences of late diagnosis in women, that I was formulating ideas about the impact of late diagnosis based on gender, when gender was not being raised as an impacting factor by the participants within the studies. Ensuring my descriptive codes and themes stayed close to the original text was important in supporting me to ensure my own knowledge and opinions did not influence the analysis. Reflecting on this has also been helpful when thinking about the design and analysis of my empirical study."

Appendix 3

Journal of Autism and Developmental Disorders Manuscript Submission Guidelines

Instructions for Authors

Editorial procedure

Double-Anonymous Peer Review

MANUSCRIPT FORMAT

All JADD manuscripts should be submitted to Editorial Manager in 12-point Times New Roman with standard 1-inch borders around the margins. Please disregard the suggestion of 10-point font in the Text section below.

APA Style

APA Publication Manual standards must be followed.

As of January 20, 2011, the Journal has moved to a double-anonymous review process. Therefore, when submitting a new manuscript, DO NOT include any of your personal information (e.g., name, affiliation) anywhere within the manuscript. When you are ready to submit a manuscript to JADD, please be sure to upload these 3 separate files to the Editorial Manager site to ensure timely processing and review of your paper:

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

Types of papers

Articles, Commentaries Brief Reports, Letters to the Editor

*JADD is no longer accepting manuscripts with only one participant or group studies without an appropriate comparison group.

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

Review your manuscript for these elements

1. Order of manuscript pages:

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

2. JADD submissions should include:
    - A structured abstract with the Purpose, Methods, Results, and Conclusion.
    - COI and other author statements placed on the title page.
    - No more than 40 double-spaced pages, including double-spaced references (with hanging indents), tables, and figures.
    - Tables and Figures placed at the end of the manuscript with callouts in the text.

Manuscript Submission

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

Permissions

Authors wishing to include figures, tables, or text passages that have already been published elsewhere are required to obtain permission from the copyright owner(s) for both the print and online format and to include evidence that such permission has been granted when submitting their papers. Any material received without such evidence will be assumed to originate from the authors.

Online Submission

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

Source Files

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

Suggestions for Inclusive Language in JADD Submissions

JADD Inclusive Language Guide (Download pdf, 134 kB)

Title Page

Please make sure your title page contains the following information.

Title

The title should be concise and informative.

Author information

- The name(s) of the author(s)
- The affiliation(s) of the author(s), i.e. institution, (department), city, (state), country
- A clear indication and an active e-mail address of the corresponding author
- If available, the 16-digit ORCID of the author(s)

If address information is provided with the affiliation(s) it will also be published.

For authors that are (temporarily) unaffiliated we will only capture their city and country of residence, not their e-mail address unless specifically requested.

Large Language Models (LLMs), such as ChatGPT, do not currently satisfy our authorship criteria. Notably an attribution of authorship carries with it accountability for the work, which cannot be effectively applied to LLMs. Use of an LLM should be properly documented in the Methods section (and if a Methods section is not available, in a suitable alternative part) of the manuscript.

Abstract

Please provide a structured abstract of 150 to 250 words which should be divided into the following sections:

- Purpose (stating the main purposes and research question)
- Methods
- Results
- Conclusion

Keywords

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

Statements and Declarations

The following statements should be included under the heading "Statements and Declarations" for inclusion in the published paper. Please note that submissions that do not include relevant declarations will be returned as incomplete.

- Competing Interests: Authors are required to disclose financial or non-financial interests that are directly or indirectly related to the work submitted for publication. Please refer to "Competing Interests and Funding" below for more information on how to complete this section.

Please see the relevant sections in the submission guidelines for further information as well as various examples of wording. Please revise/customize the sample statements according to your own needs.

Text

Text Formatting

Manuscripts should be submitted in Word.

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

Headings

Please use no more than three levels of displayed headings.

Abbreviations

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

Footnotes

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

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

Acknowledgments

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

Body

- The body of the manuscript should begin on a separate page. The manuscript page header (if used) and page number should appear in the upper right corner. Type the title of the paper centered at the top of the page, add a hard return, and then begin the text using the format noted above. The body should contain:
- Introduction (The introduction has no label.)
- Methods (Center the heading. Use un-centered subheadings such as: Participants, Materials, Procedure.)
- Results (Center the heading.)
- Discussion (Center the heading.)

Headings

Please use no more than three levels of displayed headings.

Level 1: Centered

Level 2: Centered Italicized

Level 3: Flush left, Italicized

Footnotes

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

Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data).

Footnotes to the title or the authors of the article are not given reference symbols. Always use footnotes instead of endnotes. Type all content footnotes and copyright permission footnotes together, double-spaced, and numbered consecutively in the order they appear in the article. Indent the first line of each footnote 5-7 spaces. The number of the footnote should correspond to the number in the text. Superscript arabic numerals are used to indicate the text material being footnoted.

Terminology

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

References

Citation

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

- Negotiation research spans many disciplines (Thompson, 1990).
- This result was later contradicted by Becker and Seligman (1996).
- This effect has been widely studied (Abbott, 1991; Barakat et al., 1995; Kelso & Smith, 1998; Medvec et al., 1999).

Authors are encouraged to follow official APA version 7 guidelines on the number of authors included in reference list entries (i.e., include all authors up to 20; for larger groups, give the first 19 names followed by an ellipsis and the final author's name). However, if authors shorten the author group by using et al., this will be retained.

Reference list

The list of references should only include works that are cited in the text and that have been published or accepted for publication. Personal communications and unpublished works should only be mentioned in the text.

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

Journal names and book titles should be italicized.

If available, please always include DOIs as full DOI links in your reference list (e.g. "https://doi.org/abc").

- Journal article Grady, J. S., Her, M., Moreno, G., Perez, C., & Yelinek, J. (2019). Emotions in storybooks: A comparison of storybooks that represent ethnic and racial groups in the United States. Psychology of Popular Media Culture, 8(3), 207–217. https://doi.org/10.1037/ppm0000185
- Article by DOI Hong, I., Knox, S., Pryor, L., Mroz, T. M., Graham, J., Shields, M. F., & Reistetter, T. A. (2020). Is referral to home health rehabilitation following inpatient

rehabilitation facility associated with 90-day hospital readmission for adult patients with stroke? American Journal of Physical Medicine & Rehabilitation. Advance online publication. https://doi.org/10.1097/PHM.0000000000001435

- Book Sapolsky, R. M. (2017). Behave: The biology of humans at our best and worst.

Penguin Books.

- Book chapter Dillard, J. P. (2020). Currents in the study of persuasion. In M. B. Oliver, A. A. Raney, & J. Bryant (Eds.), Media effects: Advances in theory and research (4th ed., pp. 115–129). Routledge.
- Online document Fagan, J. (2019, March 25). Nursing clinical brain. OER Commons. Retrieved January 7, 2020, from https://www.oercommons.org/authoring/53029-nursingclinical-brain/view

Tables

- All tables are to be numbered using Arabic numerals.
- Tables should always be cited in text in consecutive numerical order.
- For each table, please supply a table caption (title) explaining the components of the table.
- Identify any previously published material by giving the original source in the form of a reference at the end of the table caption.
- Footnotes to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data) and included beneath the table body. Each table should be inserted on a separate page at the back of the manuscript in the order noted above. A call-out for the correct placement of each table should be included in brackets within the text immediately after the phrase in which it is first mentioned. Copyright permission footnotes for tables are typed as a table note.

Figure Lettering

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

Figure Numbering

- All figures are to be numbered using Arabic numerals.

- Figures should always be cited in text in consecutive numerical order.
- Figure parts should be denoted by lowercase letters (a, b, c, etc.).
- If an appendix appears in your article and it contains one or more figures, continue the consecutive numbering of the main text. Do not number the appendix figures,"A1, A2, A3, etc." Figures in online appendices [Supplementary Information (SI)] should, however, be numbered separately.

Figure Captions

- Each figure should have a concise caption describing accurately what the figure depicts. Include the captions in the text file of the manuscript, not in the figure file. □ Figure captions begin with the term Fig. in bold type, followed by the figure number, also in bold type.
- No punctuation is to be included after the number, nor is any punctuation to be placed at the end of the caption.
- Identify all elements found in the figure in the figure caption; and use boxes, circles, etc., as coordinate points in graphs.
- Identify previously published material by giving the original source in the form of a reference citation at the end of the figure caption.

Figure Placement and Size

- Figures should be submitted within the body of the text. Only if the file size of the manuscript causes problems in uploading it, the large figures should be submitted separately from the text.
- When preparing your figures, size figures to fit in the column width.
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- For small-sized journals, the figures should be 119 mm wide and not higher than 195 mm.

Figure caption sheet

The figure caption sheet contains a list of only the captions for all figures used. Center the label "Figure Captions" in uppercase and lowercase letters at the top of the page. Begin each caption entry flush left, and type the word "Figure", followed by the appropriate number and a period, all in italics. In the text of the caption (not italicized), capitalize only the first word and any proper nouns. Table notes: Copyright permission footnotes for figures are typed as part of the figure caption.

- Each figure should appear on a separate page. The page where the figure is found should have the figure number and the word "top"[ie, Figure 1 top] typed above the figure. Figures or illustrations (photographs, drawings, diagrams, and charts) are to be numbered in one consecutive series of arabic numerals. Figures may be embedded in the text of a Word document. Electronic artwork may be in the TIFF, EPS or Powerpoint format (best is 1200 dpi for line and 300 dpi for half-tones and gray-scale art). Color art should be in the CYMK color space. *** After first mention in the body of the manuscript, a call-out for the correct placement of each figure should be included in brackets on a separate line within the text.

Section Two: Empirical Paper

Experiences of individuals with a diagnosis of personality disorder being diagnosed with autism spectrum condition whilst in secondary mental health services

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Doctorate in Clinical Psychology

Division of Health Research

Lancaster University

Word count (excluding references, tables, and appendices): 7999

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Prepared for submission to Autism
Please refer to Appendix 7 for ‘Manuscript Preparation’ guidelines

Declarations of interest: none

Abstract

Increased rates of autism spectrum condition (ASC) diagnosis in adulthood have been observed within the UK. For those diagnosed in adulthood, initial diagnoses of mental health difficulties are commonly given, including personality disorders (PD). This study aimed to explore the lived experiences of accessing secondary mental health services (SMHS) from the perspective of autistic adults who were initially diagnosed with a PD. Six autistic adults took part in semi-structured interviews, which were recorded and transcribed before being analysed using Interpretative Phenomenological Analysis. The analysis generated four themes: (1) Realising the nuances of having a diagnosis and having a diagnostic label, (2) "A steep learning curve": seeking understanding amongst misconceptions, (3) Having a voice in secondary mental health services: a dichotomy of control and helplessness, and (4) Compassion cultivates compassion: service and individual level disparities in care. The research highlighted negative experiences in SMHS across the two diagnoses. Clinical implications consider the roles of stigma and misconceptions, alongside existing best practice guidelines.

Keywords: autism, personality disorder, secondary mental health services, lived experience

Introduction

The National Institute for Health and Care Excellence (NICE) describes Autism Spectrum Condition (ASC) as a lifelong neurodevelopmental condition with a prevalence rate of 1% across the lifespan. Core features of ASC include “persistent difficulties in social interaction and communication and the presence of stereotypic behaviours, resistance to change or restricted interests” (NICE, 2012). Perspectives from the neurodivergent community describe challenges associated with ASC as mutual difficulties rather than impairments specific to ASC. For example, reduced theory of mind is commonly associated with ASC, but has been described by one autistic researcher as mutual difficulties in relating that exist between neurodivergent and neurotypical individuals (Milton, 2014). It has been argued that the deficit-based language within the medical model of ASC, as opposed to more positive language associated with a social model of disability, may be exacerbating challenges experienced by autistic people, including mental health difficulties (Woods, 2017).

Changes in the diagnostic criteria for ASC within the Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-V) (American Psychiatric Association, 2013) have contributed to an increased number of adults being diagnosed with ASC (FusarPoli et al., 2020). Adults and females have been highlighted as the populations with the highest increase in incidences of ASC diagnosis in the UK between 1998–2018 (Russell et al., 2022). ASC being missed during childhood has been hypothesised as a causal factor for the increased number of late diagnoses. It is suggested that initial presentation to services in childhood is often related to a co-morbid mental health difficulty which overshadows ASC, particularly in females (Aggarwal & Angus, 2015; Fusar-Poli et al., 2022).

One study exploring undiagnosed ASC reported that 75.4% of participants had their ASC missed during their first mental health evaluation, most of whom received treatment for a mental health condition (Gesi et al., 2021). The average time between initial mental health evaluation and a diagnosis of ASC for these individuals was eight years. Individuals whose diagnosis of ASC was given later in life have described their diagnosis as empowering, improving their life through increased understanding of their difficulties, and helping to reduce distress associated with mental health difficulties (Leedham et al., 2019; Seers & Hogg, 2023; Wilson et al., 2023).

NICE (2012) outlines recommendations for treating co-existing mental health conditions for autistic adults within their autism clinical guidance. The guidelines outline that the co-occurring mental health disorders should be treated by following the associated NICE guidelines, with adaptations to make the intervention more accessible. Qualitative literature highlights, however, that this is not necessarily the experience of those with lived experience of receiving a diagnosis of ASC after an initial mental health diagnosis. Autistic individuals reported that professionals involved in their care did not believe they had ASC, and described therapy to treat the previously diagnosed mental health condition as ineffective (Went, 2016).

Autistic individuals, including those querying a diagnosis of ASC, have been found to be more likely to disagree with their mental health diagnoses than non-autistic individuals (Au-Yeung et al., 2018). Qualitative research has revealed that some autistic individuals describe their mental health diagnoses as misdiagnoses and have experienced being misdiagnosed as detrimental to their wellbeing (Bargiela et al., 2016; Went, 2016). Furthermore, realising a diagnosis of ASC in adulthood can have a positive impact on wellbeing through allowing the individual to dissociate themselves from mental health diagnoses (Stagg & Belcher, 2019).

Personality Disorders (PD) have been found to be a frequently occurring mental health condition diagnosed within the ASC population (Fusar-Poli et al., 2020), including borderline and schizoid PDs. This was not reflected in a recent meta-analysis by Lai et al. (2019), however the analysis excluded papers that only investigated “lifelong” diagnoses, which PD’s have historically been conceptualised as (Biskin, 2015), though this understanding is changing as traits associated with PD have been acknowledged to resolve over time (APA, 2013).

Social and emotion regulation difficulties have been identified as overlapping features of ASC and PDs (Gordon et al., 2020), alongside an increased vulnerability to trauma (Dell’Osso et al., 2023). The risk of suicide and exposure to physical and sexual abuse often associated with PDs has also been found to be linked with ASC traits, with higher risk associated with the presence of ASC traits in individuals diagnosed with PD (Dell'Osso et al., 2018). These overlapping diagnostic criteria, alongside clinicians’ reported lack of confidence and knowledge diagnosing autism (Corden et al., 2022), may explain misdiagnosis of PDs when prescriptive, diagnostic approaches to assessment are followed.

Stigma surrounding PD diagnoses is well documented (Lamph et al., 2022; McKenzie et al., 2021), and may influence an autistic individual’s decision to reject the diagnosis as a misdiagnosis. However, mental health professionals may understand the two diagnoses as comorbidities (Powell et al., 2024). This disparity in the understanding of whether ASC is a comorbid diagnosis or a diagnosis that replaces an incorrect PD diagnosis may have detrimental effects for autistic adults. PD stigma has been associated with shortcomings in the care provided to individuals with the diagnosis (Klein et al., 2022). One review exploring the literature investigating mental health professionals’ attitudes towards BPD highlighted that professionals had attitudes that were more negative overall towards those with BPD than those with other diagnoses such as depression (McKenzie et al., 2022).

Positive experiences of relationships with mental health professionals can increase the effectiveness of mental health treatment (Horvath et al., 2011). This impact has been evidenced within the research for both PD (Bedics et al., 2015) and ASC (Brewe et al., 2021) interventions. However, perhaps due to stigma associated with the diagnoses, autistic adults and adults diagnosed with PDs report difficult experiences within secondary mental health services. Adults diagnosed with PD experience difficulties with staff (Rogers & Dunne, 2011) and a lack of knowledge about PD (Barr et al., 2020) as contributing factors to their challenges within mental health services. Similarly, autistic adults report a lack of understanding of ASC amongst mental health service staff (Powell & Acker, 2016) and difficulties relating to staff members (Maloret & Scott, 2018) within secondary mental health services. There is an absence of the experiences of those diagnosed with PD and ASC within the literature exploring secondary mental healthcare experiences, despite this being a common comorbidity or pattern of misdiagnosis.

The experiences of autistic adults accessing secondary mental health services, the care provided, and adapting treatment to account for ASC has yet to be explored from the point of view of those receiving such care having previously been diagnosed with a PD. This study aims to explore the secondary mental healthcare experiences of autistic adults diagnosed with a PD. Two questions will be addressed within the research: (1) Do individuals with a diagnosis of PD who are later diagnosed with ASC experience adaptations of their care related to their ASC diagnosis? and (2) Do individuals with a diagnosis of PD who are later diagnosed with ASC experience changes in their relationship with secondary mental health services post ASC diagnosis?

Method

Design

The study aimed to explore the lived experiences of secondary mental health services (SMHS), including the common themes within the sample and the range of experiences across the sample. Interpretive Phenomenological Analysis (IPA) was chosen as the most appropriate method of analysis across the six semi-structured interviews as it allows the exploration of the meaning that individuals make of their lived experiences alongside the development of common themes across those experiences. IPA is built upon the double hermeneutic of the researcher making efforts to make sense out of the individual's attempts to make sense out of their experiences (Smith, 2011). IPA’s idiographic approach involves finding sense and meaning within personal narratives through the detailed examination of individual lived experience accounts (Smith, 2011). Using IPA, the study aimed to uncover the meaning participants made of their experiences within SMHS through in-depth analysis of their individual experiences. This study employed IPA by developing broad themes alongside more detailed, nuanced narratives of the lived experiences of secondary mental health services shared by the participants.

Participants and Recruitment

Participants were recruited initially via secondary mental health services across two NHS trusts, with a secondary recruitment phase employed following amendments submitted to the Research Ethics Committee (REC) during which participants were recruited via social media. Recruiting teams within the NHS included community mental health services and specialist personality disorder services, and the study was advertised through email correspondence with team leaders and psychologists and the researcher’s attendance at best practice group meetings.

Inclusion and exclusion criteria were developed to ensure homogeneity within the participant group, which is important given IPA’s ideographic approach which infers similarities in experiences across individual narratives (Pietkiewicz & Smith, 2014). The inclusion criteria specified that participants must have received a diagnosis of PD prior to their diagnosis of ASC, and that both diagnoses must have been received after the age of 18 due to the disagreement amongst professionals regarding the validity and ethical considerations of PD diagnoses in adolescence (Kaess et al., 2014). The ASC diagnosis must have been received within 5 years; this timeframe was chosen to allow for a good enough memory of their experiences of mental health services since the diagnosis. Information regarding whether the PD diagnosis was retained following ASC diagnosis was not sought, though this is represented within the results if raised by participants within their interviews. Experiences of secondary mental health services post PD and ASC diagnoses were essential, and each diagnosis was required to have been formally given by a qualified mental health professional. Finally, participants were required to speak and understand English due to the challenges associated with accessing suitable translators within the timeframe of the study. A screening questionnaire was provided to potential participants to collect information to ensure these criteria were met (Appendix 1).

Six autistic adults were recruited, three via NHS services and three via social media. The time elapsed between PD and ASC diagnosis varied from 4 to 19 years across the sample and is represented in Table 1. Demographics such as age, race, and ethnicity were not collected for the purpose of this study. Links between rates of PD and ASC diagnoses and the treatment of autistic adults and adults with PD associated with gender and race have been documented (Bjorklund, 2006; Dehlbom et al., 2022; Green et al., 2019; Haney, 2016; Lamph et al., 2023; Tromans et al., 2021). Collection of this demographic data may have influenced potential researcher bias during analysis due to pre-existing knowledge of these issues, and this bias may then affect potential future audiences, influencing assumptions about the experiences shared within the study based on these demographics. However, where issues pertaining to specific demographics such as gender and race were explored by participants within their narratives, they are made explicit within the analysis and results.

[INSERT TABLE 1 HERE]

Data Collection

Following determination of suitability for the study via the screening questionnaire, participants' consent was obtained via a consent form that was emailed to each participant, alongside any further information requested via the screening questionnaire, including the interview topic guide for some. Interviews were offered face to face (for those recruited via NHS services only), telephone, and Microsoft Teams (MSTeams); all participants were interviewed via MSTeams, with reasonable adjustments such as keeping cameras off during the interview. The interview topic guide (Appendix 2) was developed by the researcher in collaboration with an adult with lived experience of accessing secondary mental health services whilst diagnosed with PD, and guidance for developing an interview topic guide in IPA (Smith et al., 2009) was considered. Questions not included in the interview schedule were asked when appropriate to elicit sufficient information to address the research question. The interviews required flexibility to allow for follow-up questions to explore the issues raised in more detail when needed, including when topics were raised by the participants that had not been planned for within the interview topic guide. All interviews were recorded using MSTeams and were transcribed verbatim by the researcher.

Analysis

Many variations of analysis exist within IPA (Smith, 2007) and it is flexible as a method of analysis, with guidelines that researchers can adapt to best fit their research aims (Pietkiewicz & Smith, 2014). The Murray and Wilde (2020) method of analysis was adopted to allow the focus of the analysis to be held on the participants' experiences and meaning-making, in line with the research aim, using a method that aims to cultivate proficiency in applying the principles of IPA for novice IPA researchers. The development of initial discrete themes for each interview allowed for a deeper understanding of the meaning made by the participants through the development of individual narratives relating to the initial themes.

Interviews were analysed individually, beginning with the development of initial codes summarising the data that was relevant to the research question. Coding focused on participants' experiences and perceptions of SMHS related to their diagnosis of PD and/or ASC, particularly concerning their relationships within the services and the treatment they received. Codes were developed by making descriptive and interpretive notations alongside the transcript that stayed close to the participant's experiences and sense-making. An excerpt of this process is presented within Appendix 3.

The codes generated were then grouped with similar codes within the transcript to capture the key elements of meaning in the participant's narrative. These groups were then described through the generation of an interpretive narrative summary, and these summaries were given a title that represented the theme. Key quotes that captured the participant's experiences were presented alongside the narrative summaries, as shown in Appendix 4. The analysis was provided to the research supervisor to allow for feedback and quality appraisal.

Throughout the analysis of individual interview transcripts, the researcher used bracketing (Dörfler & Stierand, 2021) to reflect upon their own biases and assumptions and set these aside to ensure a better understanding of the participants' experiences, exemplified within the critical appraisal.

Once this process had been repeated across the six interview transcripts, initial themes were combined and grouped according to similarities in the meaning the participants made from their individual experiences to generate the final themes within the data. Individual participant themes that did not directly correspond to one final theme were disaggregated, and subthemes represented within them were grouped within the final themes with consideration to similarities in the meaning making within them. Final themes were shared and discussed with the research supervisor who advised further developing initial drafts of themes to more interpretive and less descriptive themes. The individual participant themes that contributed to each final theme are displayed in Appendix 5.

In line with the criteria for good quality IPA, themes are presented as narratives following participants' journeys through SMSH and represents convergence and divergence in their experiences (Nizza et al., 2021), exploring both shared and unique experiences within SMHS, and each theme represents the experiences of each participant (Smith, 2010).

Ethical Considerations

The study received ethical approval from the UK Health Research Authority Sheffield Research Ethics Committee (reference: 23/YH/0192) and approval to recruit from the Research and Development departments at the participating trusts. The potentially distressing nature of the topics within the interviews was considered and a distress protocol (Appendix 6) was co-produced with an adult with lived experience, and the potential distress was acknowledged at the beginning of each interview, with an opportunity for the participant to share what they would find helpful if they became distressed. Participants were informed that the researcher planned to assign them participant numbers rather than pseudonyms due to the potential additional interpretation that pseudonyms may influence associated with perceived gender; all participants were agreeable to this. All identifying information was removed from the transcripts, and all files containing personal data were stored securely.

Results

Theme 1: Realising the Nuances of Having a Diagnosis and Having a Diagnostic Label

This theme reflects the six participants' journeys through SMHS and how their experiences changed, conceptualised as changes directly related to how they were viewed by SMHS based on their diagnostic label. The impact of the PD label dominated the participants' narratives. An instant shift in how SMHS clinicians related to the participants following their PD diagnosis was sensed by the participants within their interactions with services, as described by P3 “I mean, with the PD diagnosis, it's just instant that once they know it is completely set against you”. Negative perceptions of the participants began to manifest within their interactions with SMHS, and participants began to be associated with negative labels such as “untrustworthy” (P1, P3), “manipulative” (P6), “attention seeking” (P4), and “annoying” (P5, P6). The addition of the PD label was the only thing that had changed, which clarified that it was the PD diagnosis that had inspired the change in their SMHS experiences, as described by P1: “my interactions with them changed a lot after the diagnosis, but realistically, the things I was presenting with hadn't”.

There was an acknowledgement within the participants’ narratives that they were being perceived according to the stereotypes and stigma that is associated with PD labels. This created a hostile and confusing environment for P3, who had no prior knowledge of PD stigma: “I didn't understand why, because I didn't know enough about all the stigma of it”. P1 had explored PD stigma when reading about the diagnosis online, expecting this new label to impact them negatively, “There was a lot of reading I did online at the time, and I think that gave me quite a negative outlook”. For P2, P4, P5, and P6, the realisation that they had experienced stigmatised attitudes associated with their PD label came in hindsight, and they had all initially been pleased to receive the diagnosis, as explained by P6: “I kind of latched on to it. And I was like, oh, I've got this thing. I've got BPD”.

Participants began to sense that their PD labels were overshadowing them as individuals within SMHS, presenting in the same ways they always had yet being treated differently. For P6 this was a conflicting experience as their difficulties were being legitimised, whilst at the same time experiencing invalidation based on their difficulties being associated with a PD: “… things were taken a lot more seriously, like I was offered therapy which, you know, I didn't have before… but then the complete opposite, where the people were really rude and invalidating”. At times, this escalated into experiences of treatment being accessible yet punitive: “…they treated the whole admission like I was being punished.”(P3). For others, the PD label seemed to overshadow and delegitimize their difficulties. P3 described not being believed about symptoms of their other diagnoses, “…none of the doctors believed that I had depression or anxiety at all”. Experiences of their distress becoming annoying “I felt like I was just annoying her and she didn't wanna deal with me” (P5) and their challenges being unfixable “you were treated like a problem, or unchangeable, or a revolving door patient” (P4) began to extinguish any hope held by the participants that SMHS could help them.

With this loss of hope came a need to distance themselves from the PD label, which motivated the quest for a new explanation for their difficulties: ASC. As P3 described, “It’s the removing of the stigma of personality disorder and the mistreatment. That’s what I’d really like to get out of [ASC diagnosis]”. Consequently, more weight was given to the importance of having ASC confirmed, and P2 explained “I was at the point where I was thinking, God, if they don’t give me that diagnosis, I’m just going to kill myself”. This highlights the possibility that participants expected experiences of stigma within SMHS to cease if they had a new label to replace PD, confirmed by P1 “I think there was sort of a subtle opinion that I'd probably be treated less differently”.

Following ASC diagnosis participants experienced some improvements in their interactions with SMHS “they see me differently because of the diagnosis, they’ve been so much more helpful and respectful” (P3). SMHS seemed more compassionate and supportive, and the introduction of adjustments and adaptations reinforced the legitimacy of previously dismissed challenges: “They were all really kind 'cause they understood that there was certain things that I couldn't cope with like, little things like perfume” (P5). However, participants’ experiences of being treated in accordance with their diagnostic label over their individual needs prevailed, and experiences of being treated according to assumptions based on them being autistic began to surface. Participants experienced being infantilised by SMHS staff, as described by P3:

> I've had people like, literally wave, you know, pull faces and wave at me or trying to get down on my level and they just put this little voice on, like, they're talking to a child. It’s a little bit annoying.

Participants experienced being viewed in a deficit focused light by SMHS, experiencing this as patronising “I get treated either very, very, very sensitively, like over sensitively, or spoken to almost like… I don't understand what's going on and trying to be really sort of… that's the word, patronising”.

Diagnoses and diagnostic labels were powerful forces within participants’ experiences of services, shaping their experiences through interactions stemming from assumptions, stereotypes, and stigma, whilst simultaneously acting as a helpful gateway to help and support.

Theme 2: “A Steep Learning Curve”: Seeking Understanding Amongst Misconceptions

Alongside diagnoses of PD and ASC providing them with access to support, treatment, and adaptations, participants used them to improve their understandings of their difficulties. Whilst all participants initially evaluated PD as a diagnosis that fit their experiences “I'd read about like the emotions and things and them feeling big, I was like, yeah, actually, I do feel a lot” (P4), “I googled it and I thought like, oh, this kind of makes sense” (P6), this changed with the diagnosis of a more appropriate condition, ASC. Having a diagnosis that felt like a better fit improved participants’ understanding of their difficulties “I was surprised at how much of a relief, how validating it was for me to be like I finally have answers that are right” (P2).

The confirmation of ASC influenced participants to reflect on their past, and feelings of grief and frustration surfaced through the realisation that being autistic was not identified by the services whose job it was support them to understand and overcome their difficulties.

P3 wondered how their experiences in SMHS could have been different with earlier diagnosis:

> There's quite a lot of grief, I think, thinking that I've gone such a long time and not known because I was like, nearly 42 at that point, and I've gone through all the stuff and I had known for such a long time and if I'd known earlier, maybe I would never have got as mentally unwell as I did.

In their search for an explanation for why their ASC had been undetected, participants began to question whether SMHS had a good enough understanding of their presentation and the labels often associated with it. Evaluations of SMHS holding misconceptions about PD “I found that they didn’t really know very much at all” (P5), “that [lack of understanding] is the same with PD as well to be honest” (P1) and ASC “I don't think [psychiatrist] really believes in autism in women” (P2) were used to contextualise some of the barriers participants faced in SMHS. For some, these barriers prevented them implementing skills given to improve their mental health “there was a lot of me meeting with my care coordinator weekly and going through random skills that I didn’t feel like I understood or that worked” (P4). For others, the initial misevaluation of them as meeting the criteria for a PD diagnosis was a barrier to a mutual, accurate understanding of their presentation “But like, when I got the BPD diagnosis, they said things about like impulsivity and stuff like that which like, I'm the least impulsive person ever” (P6).

As SMHS were evaluated as having inadequate understandings of their diagnoses, participants’ new understandings facilitated by their ASC diagnosis served as a mitigating factor against difficult experiences. Participants felt more able to advocate for their needs “the more I understand it’s easier for me to advocate for what I need” (P4) and began to share their new understandings with SMHS staff to tackle some of the common misconceptions “I mean, they’ve been open to the things they’ve learned from me” (P5).

Participants' quest to understand their experiences through diagnosis and SMHS support led to evaluations of SMHS as holding many misconceptions about diagnoses and presentations. As their own self-understanding developed through accurate diagnosis, participants became empowered to tackle these misconceptions through advocacy and sharing their knowledge, perhaps driven by their experience of SMHS' assumed expertise falling short of their expectations.

Theme 3: Having a Voice in Secondary Mental Health Services: a Dichotomy of Control and Helplessness

Participants held expectations of the help and support available under SMHS, and how this would be delivered post PD and post ASC diagnosis. There was an awareness of the person-centred approach that SMHS promise across the narratives, which brought a sense of hope that participants would have a voice in decisions about their care, and some participants were given some choice over their care and treatment "they started talking about putting me on an antipsychotic and gave me a couple of choices" (P2), "[DBT] wasn't like, a forced thing, it was something I really wanted to do" (P1).

For all participants, control over their care was fleeting, post PD and post ASC diagnosis. This sense of being out of control was palpable "I don't feel like I have any control over how this goes or what treatment I receive" (P4). For participants who expressed their needs more forcefully through challenging SMHS's decisions about their care, this was unanimously unsuccessful "when we challenge [SMHS] they squirm out of it and don't answer" (P2). For P1, this was experienced as a misalignment between their priorities and what SMHS held as important as they attempted to regain control over their medication "the medication was a huge part of it for me, but not for the service". When attempts to regain control through expressing preferences were unsuccessful, "it was like, well, we're not gonna admit you to hospital and we know that's what you want" (P4), participants became disillusioned with the idea that SMHS were able to deliver what they promised.

Experiences of becoming disillusioned or disappointed by services cultivated a sense of hopelessness, "there was a lot of times I almost felt helpless, but I was being helped" (P4) and participants began to disengage from services to regain control. P1's experiences post PD diagnosis left them feeling "quite disillusioned overall, and probably a lot less engaged" whilst P5 displayed a more tangible act of distancing from SMHS post ASC diagnosis "I didn't go back for a couple of weeks".

Further exertions of control were apparent within the narratives through participants' self-initiation of the ASC diagnostic process. Whilst this control was powerful and led to the desired outcome for all participants, a sense of misplaced responsibility was clear "the fact that somebody who is very clearly autistic doesn't get picked up on like, it shouldn't have been my job to notice this" (P6).

A lack of trust in SMHS developed over time, and making the decisions about whether to continue to engage with services was the participants' final opportunity to exercise control over their care. For some, this was complete disengagement from SMHS "I didn't try to seek any support from services after that" (P6) and influenced their perception of the potential usefulness of accessing SMHS in the future "I feel like I'm less likely to reach out for support" (P4). For P5, who remains under the care of SMHS, exerting their right to choose which services they engage with based on their perceived effectiveness was important "I'm not going to ring up again, because what's the point?"

Whilst being supported by SMHS came with the promise of person-centred care, the reality of being under these services left participants feeling out of control and powerless, being done to rather than done with. Whilst attempts were made to regain control, ultimately trust was eroded and participants became disillusioned and distanced themselves from SMHS, perhaps as a final attempt to take charge of their care.

Theme 4: Compassion Cultivates Compassion: Service and Individual Level Disparities in Care

Whilst navigating SMHS and the difficulties they faced within them, participants were forming an unconscious understanding about why some of their experiences within SMHS were challenging outside of their diagnoses.

At the forefront of each participant's narrative were challenging experiences within SMHS at a systemic level. Poor cultures within NHS trusts were apparent to the participants, and P2 described a trickle-down effect that shaped their experiences post PD diagnosis: "I think it stems from a specific person who is very high up in the trust and leads the policy and approach to personality disorder." Whilst it was identified that this was not an accurate depiction of all trusts "up until I moved to [new trust] my experience of mental health services was just awful" (P5), the challenging experiences within SMHS superseded the positives within the participants' narratives.

This was perhaps due to the more difficult experiences occurring mostly at times when participants were most vulnerable. These included experiences with unfamiliar services whilst in crisis "if there was a situation that required help it almost went from a gosh, let's get you some help and understand this to a look, you know what to do. Go do it" (P1); within inpatient settings where the participants were detained "they treated the whole admission like I was being punished, you know" (P3); and with psychiatrists who were appraised as powerful within their care "Really, the only person I feel like does hold me to that stigma is my psychiatrist" (P2).

Participants struggled to accept these experiences "I think the impact on how people respond to you, I don't think that that's right" (P4), and at times they were perceived as universal and were generalised across SMHS “obviously like doctors just dismiss you” (P5). Difficult emotions began to shape participants’ understanding of their experiences “I was really angry with the same people in that sense” (P1), and they began questioning their appraisals of the differences in their experiences throughout their SMHS journeys as being solely linked to their diagnosis “I can't tell if it's being under a different trust and being under different staff that's just better, or if it is having a autism diagnosis” (P3).

There was a sense that participants were mirroring qualities of the challenging interactions they experienced within SMHS within their retelling of them. Some made blanket statements about specific types of service “The worst people, absolutely liaison” (P2) and the language used to describe those they had challenging interactions with had similar qualities to the language that had been used to describe participants by SMHS “That doctor was incredibly rude and dismissive” (P3). Perhaps this is an understandable consequence of being exposed to recurrent negative experiences and interactions; as humans we learn through our observations of others.

Sparkling moments of experiencing care that was kind, compassionate, and considerate began to scatter across the narratives when the participants considered their experiences of individual, familiar clinicians within SMHS. Individuals who spent the most time with the participants, predominantly therapists, provided positive experiences “my therapist was absolutely lovely, and I really got a lot from DBT” (P6), “the two therapists that were doing it were really brilliant” (P5). For P2, the familiarity that came with long admissions to inpatient units cultivated fewer challenging experiences of care “[inpatient service] were the most understanding, I think because they see patients kind of day-to-day on the ward”.

Familiarity and the sense of safety that comes with it was perhaps the distinguishing factor between negative experiences from services and positive experiences from individuals.

As P1 described, “from a service point of view, I’ve not always felt supported at all. It’s more the people that have supported me”. When considering individuals within SMHS, P4 identified that services were not exclusively challenging to engage with: “I feel like there's always good and bad stuff and good and bad attitudes”. Participants held compassion for the understandable reasons why they may struggle to provide good experiences of care “I know how pressured the services are and stuff like that” (P6), “I think it'd be an unfair comparison given the amount of change the crisis team has gone through” (P1). The compassion and understanding shown to the participants by individuals within their SMHS interactions were mirrored in their appraisals of why they had experienced challenges.

Throughout their experiences in SMHS participants attempted to make sense of those that were challenging and did not meet their expectations. Through individual interactions with clinicians that modelled compassion and understanding, participants’ appraisals of SMHS and their experiences within them changed. Viewing SMHS through the same critical, negative lens they themselves had experienced being perceived through shifted to more compassionate, understanding conceptualisations of why clinicians within SMHS may have interacted and related to them in ways that were challenging.

Discussion

The study aimed to explore the experiences of SMHS from the lived experience perspective of autistic adults who had been initially diagnosed with a PD. Five themes emerged, which are discussed in relation to existing literature and implications for clinical practice and future research.

To understand whether experiences within SMHS changed post ASC diagnosis, it is important to consider how SMHS were experienced post PD diagnosis. The findings within the study highlighted that feeling lost behind typical views and assumptions based on the PD label was common. This is consistent with the existing literature exploring the impact of the

PD label on clinician attitudes. It has been suggested that perceptions of the ‘challenging behaviours’ associated with PD can be integrated into an overall perception of those with the diagnosis by clinicians (Aviram et al., 2006). These biases may be influenced by the label itself rather than the presentations associated with the diagnosis (Lam et al., 2016; Rogers & Dunne, 2011). This is exemplified within the literature surrounding clinicians' perspectives of working with those diagnosed with a PD, in which it is identified that objectivity is difficult, leading to biased clinical assessment and treatment (Treloar, 2009).

However, this was not exclusive to the PD label within the study, as some examples of feeling lost behind the label of ASC were explored. Participants described being treated differently by SMHS despite their presentation not changing, including being patronised and infantilised. Clinicians may experience a sense of frustration or helplessness when working with this population due to presentations often experienced as challenging including risk to self. This, alongside common pressures within NHS SMHS including increased demand (UK Parliament, 2023), may have contributed towards a sense of learned helplessness amongst SMHS staff. This is perhaps understandable given that clinicians report low confidence and knowledge when working with autistic adults in mental health services (Maddox et al., 2020). These experiences are highlighted within the existing literature as being shared by those diagnosed in childhood (Mesa & Hamilton, 2022), suggesting this is a challenge associated with the ASC label rather than being diagnosed in adulthood or exclusively within adult SMHS.

The use of diagnostic labels may be a key contributing factor to challenging experiences in SMHS regardless of the diagnosis. However, having an awareness of the pros and cons of psychiatric diagnostic labels is important, as participants acknowledged the benefits of both labels including access to therapy/services and validation of their challenges. This is supported by the research exploring service user perspectives on diagnoses

(Johnstone, 2014) and suggests that, whilst diagnoses allow for signposting and access to services and support, less prescriptive methods of assessment than the typical diagnostic approach may mitigate negative experiences in SMHS and allow for more accurate, nuanced understandings of individuals' experiences.

Participants' distress was often invalidated or dismissed when the diagnostic label attached to them was PD, which is consistent with the existing literature exploring experiences of SMHS for people with a diagnosis of PD (Lester et al., 2020; McKenzie et al., 2022; Rogers & Dunne, 2011). However, participants experienced more validation and compassion from SMHS following their ASC diagnosis. It may be that receiving an ASC diagnosis was validating for the participants (Lewis, 2016; Punshon et al., 2009), however it seems that SMHS interactions contributed to feeling validated. Further research exploring the barriers and facilitators to distress/challenges being validated for adults with a diagnosis of PD and/or ASC would be valuable in adding context to this phenomenon.

It was a common experience for participants to be treated as 'somebody with a PD' instantly following diagnosis, whilst experiencing some challenges in getting SMHS to accept or identify their autism both pre and post ASC diagnosis. It may be that SMHS clinicians experienced confirmation bias following diagnosis; seeing and interpreting the participants' presentations as confirming their evaluation of them having a PD. Research suggests that when psychiatrists make diagnoses based on confirmatory information seeking, they are at risk of making incorrect diagnoses (Mendel et al., 2011). As many of the participants described their PD diagnosis coming from them being observed to meet the diagnostic criteria, this could be seen as confirmatory information seeking and may explain why their ASC was missed. Some participants also hypothesised that their gender added an additional layer of complexity, suggesting that they may not have been diagnosed with a PD prior to having their ASC realized if they were not female. PDs have been found to be commonly misdiagnosed in autistic women (Gesi et al., 2021).

The stigma associated with the PD and ASC labels was understood as a key contributing factor to the participants' experiences in SMHS, which is common in mental health services (Barr et al., 2020; Crane et al., 2019; Ociskova et al., 2017) and was experienced by the participants within the study. This suggests that the population investigated within this study are particularly vulnerable to experiencing stigma, and therefore may be more likely to have difficult experiences within SMHS. Furthermore, it would perhaps be understandable to hypothesise that internalized stigma could be a further risk factor. Self-stigma is a common phenomenon experienced by individuals diagnosed with PD (Ociskova et al., 2023; van Schie et al., 2024) and ASC (Botha et al., 2022) contributing to decreased wellbeing.

Expectations not being met within SMHS had a negative impact on the participants' experiences across the narratives, particularly related to a perceived lack of person-centred care. Person-centred care is widely recognised as best practice within mental health settings (BPS, 2017; NICE, 2019; RCPsych, 2022), highlighting that service users should be involved in decision making, and that their preferences should be considered. This expectation was not met for some participants within this study, leaving them feeling powerless within their SMHS care, suggesting that more emphasis needs to be put on this standard within some SMHS settings.

Support being withheld or given in a way that was perceived as punishing was also a challenge for some participants. Post PD diagnosis, this was experienced as treatment being withheld if a preference for it was expressed, and treatment being weaponized to punish one participant. Research has documented treatment of people with a diagnosis of PD being experienced as punitive, particularly in inpatient settings (Chiesa et al., 2000; Rogers &

Dunne, 2011). When considering the participants' experiences post ASC diagnosis, support was identified as being withheld due to SMHS not being set up to provide postdiagnostic support. Post-diagnostic mental health support for autistic adults is challenging to access in the UK (Wigham et al., 2023), and one study found that despite NICE guidelines (NICE, 2014) most autistic adults had not experienced the recommended post-diagnostic support. However, adaptations to their SMHS care in consideration of their new ASC diagnosis was reported by some participants, in line with NICE guidelines (NICE, 2014).

Diagnosis providing improved self-understanding, and improved understanding from others, was impactful for the participants within their SMHS experiences. However, a lack of understanding from SMHS was understood as contributing to difficult experiences. Mental health nurses have reported wanting more training around working with PDs (Dickens et al., 2016), but further research is needed to examine the perceived knowledge of PDs in the UK from SMHS staff's perspective. Similarly, participants described a lack of knowledge about adult autism within SMHS that negatively impacted their experiences post-diagnosis. The importance of good knowledge of ASC within mental health services has been highlighted within the literature (Crane et al., 2019) and a lack of skills and knowledge in working with autistic people has been identified within UK inpatient settings (Jones et al., 2021).

Finally, the importance of good individual relationships within SMHS was highlighted by participants in providing good experiences amongst the bad. Working alongside staff they were familiar with was impactful, with more familiar staff providing more validating, compassionate, and person-centred care. Good relationships with staff members in SMHS have been found to correlate with an increased sense of trust and safety (Gilburt et al., 2008) and improved perceptions of quality of care (Bacha et al., 2020). Working with unfamiliar staff members, including bank and agency workers, has been reported as a barrier to SMHS settings being perceived as therapeutic (Rose et al., 2015).

Clinical Implications

The results of this study indicate that receiving care from SMHS can be challenging for people diagnosed with PD and autistic adults and highlight areas of improvement that are important to consider when working with individuals with a diagnosis of PD and/or autistic adults.

Challenging experiences within SMHS explored by the participants within this study as a direct result of the diagnostic label attached to them at the time could be understood as being caused by two key phenomena: stigma and misconceptions. Research has found that stigma reduces as knowledge and understanding about a diagnosis improves (Mavropoulou & Sideridis, 2014), and improving knowledge has been observed to be more effective than interventions that target reducing stigma (Gillespie-Lynch et al., 2015). Providing training and support to SMHS to improve their knowledge of working with autistic adults and those diagnosed with a PD is recommended to mitigate the risk of stigmatised views of the diagnoses negatively impacting SMHS care. Training including the National Autism Trainer Programme and the Knowledge and Understanding Framework is available for all NHS England mental health professionals.

Additionally, interventions to target self-stigma may be beneficial when working with this population within SMHS. Such interventions have been developed, including Narrative Enhancement Cognitive Therapy (NECT) (Yanos et al., 2011), which is available in a number of languages and has been shown to be effective in reducing self-stigma and improving self-esteem (Yanos et al., 2015).

Person-centred care was not experienced consistently across the participants' accounts, despite it being identified as good practice. Reducing thresholds for interventions for people diagnosed with a PD can ensure care goes beyond managing behaviours, including promoting joint decision making and therapeutic relationships with staff (Warrender et al., 2021). Working relationally with autistic adults to see the person beyond their ASC diagnosis is recommended within the literature (Quinn et al., 2023), and the use of relational and reflective peer supervision has been shown to be effective in increasing insight, empathy, and skills in relational practice when working with autistic adults (Hallinan & McMahon, 2024).

Post-diagnostic support was identified as important yet lacking by participants, highlighting the importance of support being available within SMHS whilst this is unavailable elsewhere. It has been identified that the post-diagnostic support priorities of autistic adults in the UK include processing the impact of late diagnosis, individualised support plans, and peer support (Crompton et al., 2022; Crowson et al., 2024). Arguably, SMHS are well placed to provide these types of support. Health Education England (HEE) has developed peer support worker guidelines (HEE, 2020) to support the implementation of peer support within mental health services, and individualised care plans are detailed within the NICE guidance for adult mental health services (NICE, 2011).

Limitations and suggestions for future research

The present study provides rich, lived experience accounts of a population that is thus far scarcely investigated within psychological research. This is important considering the increasing rates of adult ASC diagnosis and the acknowledged overlap between PDs and ASC.

Nevertheless, this study has some limitations. Firstly, the recruitment and interview methods may have excluded a proportion of the relevant population given the need for potential participants to be able to access the internet. Whilst telephone and face-to-face interviews were offered, this may have also been a barrier due to the potential impact of communicating verbally with a stranger. Future research may benefit from offering written methods of communicating qualitative information such as questionnaires. Whilst this method prevents the researcher asking for more information when needed, it could improve the accessibility of the research.

Participant demographics including gender identity, race, and ethnicity were not collected, as outlined within the method section. Whilst this served to mitigate the impact of pre-existing knowledge and biases of the researcher and future readers, important information pertaining to whom the challenges explored within the narratives affects is lost. Further quantitative research into who is likely to be affected by some of the phenomena explored within this research is recommended and would add to the existing literature which highlights who is most at risk of having their ASC missed by mental health services.

The experiences of adults who have self-diagnosed as being autistic were not explored within this study. Research suggests that many self-diagnosed autistic adults do not disclose their self-diagnosis to professionals (Pohl et al., 2020), and for those who do it is likely to be dismissed or ignored (Lewis, 2017). Therefore, it was deemed unlikely that a selfdiagnosis of ASC would impact SMHS experiences as it is likely that professionals would not consider this within their care. However, as there are many barriers to adult autism diagnosis including long waiting times (NHS England, 2023), it is perhaps to be expected that selfdiagnosis is common amongst autistic adults diagnosed with a PD and would be important to research in relation to SMHS experience.

Finally, it would be helpful to investigate the themes explored within this study from a clinician perspective to better understand the clinician attitudes and decisions that negatively impacted the SMHS experiences of the participants. Further exploring learned helplessness amongst SMHS clinicians may be useful, as this has been shown to reduce staff wellbeing (Qourrichi et al., 2024) which can lead to poor patient outcomes (Hall et al., 2016).

Conclusion

This study highlights the cyclical nature of negative experiences in SMHS being relieved temporarily by new understandings following receiving a diagnosis, and then descending back into being challenging. Stigma and misconceptions about PDs and ASC were powerful in their impact over the experiences participants had in SMHS, and ways SMHS can move forward based on clinical guidance and best practice are considered. More importantly, these considerations stem from the accounts of those with lived experience, whose voice is important yet silenced at times within SMHS.

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Table Legends

Table 1 Participant demographics

Table 1

Participant demographics

Participant Number	Age of PD diagnosis	Age of ASC diagnosis	Time elapsed between diagnoses
1	25	30	5 years
2	29	33	4 years
3	22	41	19 years
4	18	26	8 years
5	41	45	4 years
6	21	28	7 years

Section 2 Appendices

Appendix 1 Participant screening questionnaire

Appendix 2 Interview topic guide

Appendix 3 Excerpt of the initial Interpretative Phenomenological Analysis coding for participant 1

Appendix 4 An excerpt of the process of grouping participant 1’s codes into themes, including key quotes and narrative summaries

Appendix 5 Participant themes contributing to final themes

Appendix 6 Distress protocol

Appendix 7 Autism reporting guidelines

Appendix 1

Participant Screening Questionnaire

Screening questionnaire

Experiences of individuals with a diagnosis of Personality Disorder being diagnosed with Autism Spectrum Condition whilst in secondary mental health services.

Please answer the questions below to the best of your ability to enable the researcher to understand whether you meet the criteria to take part in the study. All information will remain confidential, please see the participant information sheet for further information.

Current age ________

Age at time of Personality Disorder diagnosis __________

Type of service(s) you were under at the time of the diagnosis (CMHT, Inpatient, Specialist Therapy Service etc.): _____________________

Job title of the professional who gave the diagnosis: __________________

Age at time of Autism Spectrum Condition diagnosis __________

Type of service(s) you were under at the time of the diagnosis (CMHT, Inpatient, Specialist Therapy Service etc.): _____________________

Job title of the professional who gave the diagnosis: __________________

For the purpose of the study, are you able to speak and understand English: Y ☐ N ☐☐

Is there any further information it may be helpful for the researcher to know regarding any reasonable adjustments that would improve your access to a potential Teams or telephone interview?

Appendix 2

Interview Topic Guide

Interview topic guide

Experiences of individuals with a diagnosis of Personality Disorder being diagnosed with Autism Spectrum Condition whilst in secondary mental health services.

Introduction

Thank you for joining me for the interview today. During the next hour we are going to talk about your experiences of using secondary mental health services after your personality disorder diagnosis, and after your diagnosis of autism spectrum condition.

Is there anything that it would be helpful for me to know before we start, such as anything you don't want to talk about or anything I could do that would be helpful if you feel distressed by what we are talking about?

Finally, how do you prefer the two diagnoses to be referred to when we're talking about them?

Experiences after PD diagnosis

Could you tell me about how you received your diagnosis of PD?

What information, if any, were you given about the diagnosis?

What information/choices were you given about your treatment?

What were your experiences of secondary mental health services following this diagnosis?

What were your experiences of working with staff in secondary mental health services following this diagnosis?

Experiences after ASC diagnosis

Could you tell me about how you received your diagnosis of ASC?

What information, if any, were you given about the diagnosis?

What was your response/feelings about receiving this diagnosis?

What was the response of the team whose care you were under at the time?

What information/choices were you given about your treatment?
EXPERIENCES OF PD AND ASC IN SMHS

Were there any changes to your treatment following this diagnosis?

Did you notice any difference in your experiences with staff following this diagnosis?

Were there any other changes you noticed in your experiences with secondary mental health services following this diagnosis?

What were your expectations in terms of how your experiences in secondary mental health services might change following this diagnosis?

Appendix 3

Excerpt of the Initial Interpretative Phenomenological Analysis Coding for Participant 1

Initial Data Coding: Participant 1 Transcript and Initial Codes

Transcript	Initial Codes
P1: I think my expectations, I probably didn't put too much thought into like specifically thinking I expect this to change by doing this, but I think there's sort of a subtle opinion that I'd probably be treated less differently, but I think that was more about if I had, if I was autistic rather than PD, PD would be removed, which wasn't the case. So, I think it's just my interpretation of things. My expectation was different. Oh, it was very much about the treatment, if anything, of the treatment of me rather than the treatment of my health. I: Yes, that makes sense. Yeah. So more of how people treated you as a person rather than the treatment they offered for your health. Yeah. OK. And did you find that those with those expectations met atall, or did you	experience anything that was just really not what you expected? P1: I guess to begin with, I think it was met because I think even the initial diagnosis letter set out a really good, there's the diagnosis letter 67. Subconsciously expecting to be treated differently to how they were treated following the PD diagnosis 68. Expecting PD diagnosis to be removed following autism diagnosis 69. Expectations not matching reality 70. Expectation of change centred around the treatment of the person rather than the treatment of their mental health

to the GP and there's actually like a pages and pages and stuff for me to consider, and support and things. Very much charity based support, but still like things from this provider that they say, and one of the things it mentioned at the top of the diagnosis letter was obviously autism spectrum disorder, and does not present as personality disorder. I remember that being the next line, and I remember thinking that's like a really good thing for me. But I also remember a conversation, probably more primary care with my GP a few months after where they wouldn't take, not take it off, but they wouldn't mark it as an old diagnosis.

71. Expectations of change met instantly due to post-diagnostic information

72. Possibility of PD diagnosis being removed: “that’s a really good thing for me”

Because it wasn't the same person or same service that had given me that was wanting to change it. And when you see a list of my diagnoses now, it's a, you know, it's like hypertension and stuff. But it'll say depression, anxiety, personality disorder, autism and, and those look like the like, four or five diagnosis I currently have when that's not really reflective of how I present sometimes.

73. PD diagnosis not removed

I: I'm going to ask a question now that I'm going to ask you to consider from both time periods, if that's OK? So, I’ll ask the question, then I'll ask you to speak about either after the personality disorder diagnosis or the autism diagnosis, whichever you'd prefer to talk about first, I guess. But just thinking in terms of both diagnoses if there was any impact on

those diagnosis and what you learn about them subsequent to them, that helped you make sense of some of your experiences?	way of support or stuff. It was more just here's your diagnosis, here's your discharge letter from the autism service. But I think the research I've
P1: So I think, I think it's polar opposites of both diagnosis, so I think when I initially got the personality disorder diagnosis, which I'll do first, I think I initially didn't really have much in the way of insight about myself. It was just a lot of different, like confusing things going on, a lot of symptoms that I was just living with. And I think when I got that diagnosis, it gave me that understanding, but a lot more understanding that was very harmful to me and my mental health. So I think if anything, getting that diagnosis made it worse, but that's more because the support and things that I got from services at the time wasn't really that much until the DBT side, so I think if I got the diagnosis in what, 2016, referred to DBT about 2018, there's like a two year period there where I didn't really have, I just had a diagnosis and just, you know, wild interactions with services, and I think that was difficult for me. With the autism diagnosis, again, I didn't, I didn't really get too much, like, certainly not from the NHS, I didn't get anything in in the done for that and the support that this provided around information was	75. Polar opposite experiences of each diagnosis' impact on understanding of mental health understanding 76. PD diagnosis facilitated understanding in a way that was harmful 77. Negative impact of PD diagnosis linked to lack of support 78. "I just had a diagnosis and just, you know, wild interactions with services, and I think that was difficult for me." 79. Similar lack of support following autism diagnosis

really helpful to me in understanding actually, yes, this does explain all these different things rather than me thinking there's all these things I didn't know about that I now have. It was more an explanation rather than a realisation.	80. Support following autism diagnosis facilitated understanding of mental health difficulties 81. Autism was “more an explanation rather than a realisation.”

Appendix 4

An Excerpt of the Process of Grouping Participant 1's Codes into Themes, Including Key Quotes and Narrative Summaries

Codes grouped into theme	**Theme title**	**Narrative summary**	**Key quotes**
• Experiences in secondary services factored into PD diagnosis (code 2) • Potential of autism recognised by SMHS staff member as some experiences didn't make sense from a PD point of view (code 37) • Diagnosis defines who you are in SMHS (code 59)	'Getting a diagnosis, suddenly you become a definition': losing your identity to a label.	This theme reflects participant 1's experiences of their diagnoses overshadowing them as an individual within SMHS. They seem to understand both diagnoses as being a product of SMHS observing their experiences and interactions with SMHS and making sense of them in relation to their expert knowledge of the diagnostic criteria for PD, and when that didn't sufficiently encapsulate all their experiences, ASC. Participant 1 experienced	'they diagnosed me in 2016, I think, from a consultant psychiatrist point of view, after quite a few different sessions and things, going through that as well as like medical units and stuff, and I think there's a lot of A&E admissions around that time which they factored into it all.' 'there was some conversations with my care-co about things

• You are seen as your diagnostic labels within SMHS (code 61) • Negative experiences with secondary mental health services post PD diagnosis understood as relevant to the new diagnostic label rather than any other context. (code 24) • Interactions with crisis SMHS changed after PD diagnosis (code 26) • Autism factors into responses from SMHS (code 55)		being defined by both of their diagnoses within secondary mental health services, becoming a personification of a diagnostic label rather than the characteristics that led to the diagnosis being viewed as one component of who they are. This change in how they were viewed ultimately changed how they were interacted with by SMHS, which was experienced for both diagnoses in unique ways, but understood as relevant to the new diagnostic label rather than any other context for both PD and ASC. These changes seemed to bring with them a sense of being	that didn't make sense from a PD point of view' 'getting a diagnosis, suddenly you become a definition' 'as soon as I got it, it's all "you are this"' 'I immediately was told, like, I was lying… and that I feel was very much relevant to the diagnosis rather than any previous thing.'

• PD diagnosis having a negative impact on SMHS trust in you (code 83) • Autism diagnosis leading to being treated more sensitively (code 48) • Feeling patronised by professionals following autism diagnosis (code 49) • Treated differently though presentation hadn't changed (code 28) • Feeling anger about the way they were treated (code 85) • Feeling dismissed (code 57)		treated as if they had become a new person as they were given a new diagnostic label, becoming less trustworthy as a 'personality disordered' person, and becoming more sensitive and naïve as an autistic person. This was experienced alongside knowing in themselves that they hadn't changed, nor had the things they needed support from SMHS for, leaving them feeling angry and dismissed, and tarnishing their experience of realising an ASC diagnosis, which is commonly experienced amongst autistic adults as a positive experience. These	'I think that actually the autism did factor into that quite a lot from their response.' 'they also think I was probably trying to pull a fast one' 'I get treated either very, very, very sensitively, like over sensitively, or spoken to almost like… I don't understand what's going on and trying to be really sort of… that's the word, patronising.'

• Autism diagnosis experienced as negative due to how SMHS professionals treat me because of it (code 47) • SMHS considering adjustments for the person rather than the diagnosis: "It's always very considerate" (code 65) • Understanding that some of the changes are due to SMHS changes and not the individual or diagnoses (code 86) • Experiences with secondary mental health services changed after PD diagnosis,		difficult experiences of losing themselves to diagnostic labels did not distract from the glimmers of being seen as Participant 1 within some SMHS, and Participant 1 held a compassionate stance for the factors outside of their changing diagnoses that impacted these experiences, including changes at a service level. This was perhaps due to their acknowledgement that this experience was not exclusive to SMHS, and that it was a more challenging experience within other aspects of their life.	'realistically, the things I was presenting with hadn't changed' 'I was really angry with the same people in that sense, I guess, which is a good example of treating me very differently' 'I think it's turned into quite a negative experience, but only from the way I feel other people treat me because of it.' 'It's always very considerate.'

but less so than with other services e.g. general healthcare (code 22). -			‘I think it'd be an unfair comparison given the amount of change the crisis team has gone through.’ ‘I think that my experience with health services overall changed in different ways, secondary mental health services a lot less than other health services.’
- Sparce official information leading to exploring online recourses such as social media and forums (code 10) - Information around PD was informal and led by the	‘Am I a really bad person?’: perpetuating, pathologizing, and diminishing stigma	This theme represents Participant 1’s journey through the experience of PD stigma to feeling freed by their ASC diagnosis, and the impact of this on their mental health and subsequently their mental health	‘I wasn't given any information like formally at all.’ ‘I found like a few NHS sort of leaflets and things online, but

individual seeking the information (code 6) • Self directed exploration of PD diagnosis leading to a negative outlook (code 9) • Negative impact of PD diagnosis linked to lack of support (code 77) • Stigma internalised and changed the focus of mental health service contact (code 12) • Service attempts to pathologise the consequences of PD stigma (code 14)		treatment. Participant 1's relationship with PD stigma originated outside of SMHS, leading to difficult thoughts and feelings about themselves that manifested in SMHS contacts. A lack of information about PD following diagnosis inspired Participant 1 to seek this information themselves, inevitably leading them to uncover the many stigmatised perspectives of those who are labelled with PD. This inspired a negative outlook on the newly acquired diagnosis and, paired with a lack of post diagnostic support, the participants mental	most of it was like forum posts or Reddit or something.' 'There was a lot of reading I did online at the time, and I think that gave me quite a negative outlook' 'getting that diagnosis made it worse, but that's more because the support and things that I got from services at the time wasn't really that much' 'Having that diagnosis meant that the things I was saying were

• Impact was targeted by mental health service rather than the stigma itself (code 13) • Feeling like a waste of space (code 33) • Feeling like a waste of time (code 27) • Feeling like people thought they were a bad person because of the PD diagnosis (code 50) • Changes in SMHS responses escalated MH crises (code 35) • Changes in experiences with SMHS post diagnosis		health deteriorated. This was understood by the participant as a product of internalizing the stigma attached to their PD diagnosis and changed the focus of their SMHS support. Here, Participant 1 felt a disconnect between his hopes, to be supported through the impact of the internalized stigma, and the SMHS understanding of his experiences as being a symptom of his diagnosis. This ultimately led to their presentation of internalized stigma being misinterpreted and pathologized. This internalized stigma was experienced by	more about how much I like, felt bad or hated myself' 'I've read this, I must be a really terrible person type thing with them, sort of, them dealing with, well, why do you feel that way, and sort of like CBT to a certain extent around it.' 'I felt like I was a waste of space by calling.' 'I felt I was a waste of time'

reinforced the internalised stigma. (code 36) • Possibility of PD diagnosis being removed: "that's a really good thing for me" (code 72) • Autism diagnosis leading to feeling more normal (code 46) • Similar lack of support following autism diagnosis (code 79) • Sense making of an autism diagnosis through self-directed learning (code 43) • Adjustments requested for difficulties shut down with just the PD diagnosis (code 90)		Participant 1 as a shadow over their later SMHS contacts, carrying ideas of being a waste of space and time with them, which were perpetuated by how they were responded to by SMHS staff, further impacting their mental health. The ASC diagnosis provided a light at the end of the tunnel for Participant 1, allowing them the possibility to disconnect from the PD label and the associated stigma, feeling more 'normal'. Whilst history repeated for Participant 1 with limited support following the ASC diagnosis leading to self-directed exploration of ASC	'I felt like the experiences were people thinking I was a bad person' 'I think that's what sort of reinforced it really is like, reading it's one thing, and sort of thinking, oh, God, am I really bad person, but then almost it reinforced, made me think, oh, actually I am like.' 'I feel like I'm a real burden here, and that sort of escalated it a lot quicker.'

• Same adjustment requested with the autism diagnosis was facilitated (code 91) • Autism diagnosis giving opportunities to explore more about self in therapy (code 53)		online, silver linings continued to emerge. They were able to start accessing adjustments that had been denied when they had been requested when they had a diagnosis of PD, which perhaps cemented that the stigma associated with a PD diagnosis had played out for them within their SMHS journey prior to their ASC diagnosis. Further opportunities to learn more about themselves presented in therapy were facilitated by their new ASC diagnosis, allowing them to understand themselves in a new	'…does not present as personality disorder. I remember that being the next line, and I remember thinking that's like a really good thing for me.' 'I felt more normal than I ever have' 'It was more just here's your diagnosis, here's your discharge letter from the autism service.' 'I did a lot of reading on it and realised a lot of the things made sense'

		light, free from the shadow of PD stigma.	‘it was almost like, not a celebration, that doesn't sound right, but more of a an opportunity to explore more about myself’
• Information about treatment was really structured (code 7) • Participant was given agency in accessing treatment through co-authoring their referral (code 17) • Therapeutic treatment was wanted rather than forced (code 18)	‘I find it really ironic’: a dichotomy of control and helplessness.	This theme explores Participant 1’s journey from hopeful expectations of being helped to disillusionment with SMHS. Participant 1’s diagnosis of PD signalled the beginning of an inconsistent experience of expectations of SMHS being met, having to navigate a dichotomy of feeling in control and feeling	‘…one of the people who worked at that place started talking about the DBT referral, and that's when they gave a lot of information, really structured at that point.’ ‘I ended up writing my own referral with my care-co.’

• Contact with some service staff was mandatory (code 5) • Medication treatment changes were not in the individual’s control (code 15) • SMHS priorities did not align with the individual’s priorities (code 19) • Attempts at challenging treatment decisions were unsuccessful (code 20) • Feeling helpless despite being helped (code 84) • Shift from feeling helped to feeling like a burden (code 34)		powerless simultaneously. Post PD diagnosis the information and control given to Participant 1 varied, from limited information about the diagnosis and structured information about treatment, to full control over their therapy referral with no voice in medication changes. Whilst the glimpses of person centred care and autonomy were identified and appreciated by Participant 1, the areas they had a voice in did not align with where they wanted more control, which was understood as a disconnect between their priorities and those of the SMHS. Attempts	‘Because it wasn't like a forced thing. It's something I really wanted to do’ ‘…every three to six months there’d be this doctor that I had to go see.’ ‘…prescription goes out, now what you'll do is this now, this in six months, and etcetera…’ ‘The medication was a huge part of it for me, but not for like the service’

• Subconsciously expecting to be treated differently to how they were treated following the PD diagnosis (code 67) • Expecting PD diagnosis to be removed following autism diagnosis (code 68) • Expectation of change centred around the treatment of the person rather than the treatment of their mental health (code 70) • Expectations of change met instantly due to post-diagnostic information (code 71)		were made to challenge decisions made without input from Participant 1, however these were unsuccessful, and there was a felt sense of being helpless whilst being helped and being a burden. These experiences continued post ASC diagnosis, with Participant 1 having a subconscious expectation that the way they were treated by SMHS would change, in part due to an expectation that their PD diagnosis would be rescinded. These expectations stemmed from a belief that SMHS provided person centred care to individuals rather than their diagnostic labels, which	‘The medication side I've challenged a couple of things because I wasn't overly keen on certain side effects’ ‘I think there was a lot of times before where I felt almost helpless, but I was being helped.’ ‘…actually I feel like I'm a real burden here’

• PD diagnosis not removed (code 73) • Expectations not matching reality (code 69) • Changes in SMHS treatment post autism diagnosis led by the individual (code 66) • Service understanding of diagnoses being comorbid do not reflect current presentation (code 74) • Becoming disillusioned with SMHS (code 31)		Participant 1 identified was something that SMHS proudly state. An illusion of this expectation being met through post diagnostic information about ASC inspired hope in Participant 1, however this was shattered when the PD diagnosis was not rescinded as expected. Whilst some sense of control remained for Participant 1 within the changes to their treatment post ASC diagnosis, the disparity between their understanding of their experiences and how they were conceptualised by SMHS maintained their feelings of helplessness. These continued	'I think there's sort of a subtle opinion that I'd probably be treated less differently' 'I think that was more about if I had, if I was autistic rather than PD, PD would be removed, which wasn't the case.' 'Oh, it was very much about the treatment, if anything, of the treatment of me rather than the treatment of my health.' 'I guess to begin with, I think it was met because I think even

• Changes in perception of SMHS lead to a reduction in engagement (code 32) • Irony in the disparity between what SMHS say and what they do (code 60) • The same differences in treatment wouldn't happen between two physical health diagnoses (code 93)		experiences of feeling helpless whilst clinging to opportunities to take control over their care ultimately lead to a journey of becoming disillusioned with SHMS, and Participant 1 attributed their declining engagement with SMHS to this. This experience has helped to shape participants perspective of SMHS, identifying the irony in what services say they do versus what they have done, amplified by their knowledge and experience that this is does not have to be the way things are as it appears to them to be exclusive to mental health care.	the initial diagnosis letter set out a really good, there's the diagnosis letter to the GP and there's actually like a pages and pages and stuff for me to consider, and support and things.' 'My expectation was different.' '…they wouldn't take, not take it off, but they wouldn't mark it as an old diagnosis.'

			‘…it would more be me leading any change that was needed than anything.’ ‘…those look like the like, four or five diagnosis I currently have when that's not really reflective of how I present sometimes.’ ‘I felt that would I became quite disillusioned overall, and probably a lot less engaged.’ ‘I find it really ironic that in an industry or healthcare setting

			where people are sort of saying diagnoses don’t matter because you are who you are… those same people treat you very differently based on [diagnosis].’ ‘Yeah, especially if you turn up to a mental health service and said, oh, I don't know, I've got high blood pressure. You wouldn't really expect to be treated very differently before and after that diagnosis.’

Appendix 5

Participant Themes Contributing to Final Themes

Bold – Individual Themes

Italic – Individual subthemes

Final Theme	P1	P2	P3	P4	P5	P6
Realising the Nuances of Having a Diagnosis and Having a Diagnostic Label	**‘Getting a diagnosis, suddenly you become a definition’: losing your identity to a label.** **‘Am I a really bad person?’: perpetuating, pathologizing,**	**Dynamic relationships with diagnoses and SMHS** *Trust-wide poor culture around PD* *BPD stigma in SMHS*	**‘she’s just another PD’: The power of labels in SMHS** **‘Instant hostility and suspicion’: developing narratives about the self and others in SMHS**	**‘I think it’s sad’: Labels dictating experiences** *PD is problem focussed*	**Different labels attracting different responses**	**‘you are female, you've got BPD’: Loss of individuality within SMHS** **‘I wish I'd kept a notebook of it’: Labels attracting negativity**

	and diminishing stigma *Subconsciously expecting to be treated differently to how they were treated following the PD diagnosis* *Expecting PD diagnosis to be removed following autism diagnosis* *Expectations of change met instantly due to post-diagnostic information*	*Professionals' opinions on diagnoses can affect relationships* *Uncertainty whether changing SMHS or changing diagnosis impacted change in experiences* *Staff as offensive and stigmatizing* *Put in a BPD box and left to rot*	*SMHS as threatening* *Inpatient admission felt like a punishment* *Punishment rather than help* *Wanting to remove bias and prejudice* *Relief that ASC diagnosis proved PD diagnosis was wrong*			*Biggest change in mental health was through ASC diagnosis*

		BPD label inspires further judgmental labels *Trying to get a "BPD reaction"*				
"A Steep Learning Curve": Seeking Understanding Amongst Misconceptions	**'I could actually do something about it': new understandings of existing abilities** *Autism diagnosis leading to feeling more normal* *Sense making of an autism diagnosis through*	**'A steep learning curve': the correlation between better understanding and better experiences** *Disappointment in lack of critical thinking leading to incorrect diagnosis*	**Seeking understanding amongst ignorance.** *No explanation about why PD had been given as the diagnosis* *SMHS declined to answer questions about PD diagnosis*	**'This doesn't make any sense, we're helping her': The importance of understanding for effective SMHS treatment** *More understanding = easier to*	**'They didn't really know very much at all': The impact of misunderstanding**	**'I just wanted to understand'; Knowledge and understanding as powerful tool in SMHS** *Questioning how SMHS missed ASC*

	self-directed learning *Autism diagnosis giving opportunities to explore more about self in therapy* *Charitable service noticed something SMHS didn’t* *“and I felt like they really wanted to support me in understanding myself, but also*	*Difficulty understanding therapy skills preventing them being used* *Learning how ASC affects me leading to understanding barriers to treatment* *No information about BPD given post diagnosis* *Assumption that SMHS professionals would be trained*	*Assumptions made based on incorrect PD diagnosis*	*advocate for own needs* *Needing understanding not fixing* *A lot of info from private ASC diagnostic service*		*Shouldn’t be the individuals job to recognise possible diagnoses* *Latching onto PD as an explanation for difficulties* *ASC information isn’t very neuro affirmative* *SMHS views on ASC are outdated*

	being able to support me in anything, really, as usual” *Support feeling excessive as a result of autism diagnosis.*	*in neurodivergence*				
Having a Voice in SMHS: a Dichotomy of Control and Helplessness	**‘I find it really ironic’: a dichotomy of control and helplessness.** *Same adjustment requested with the autism diagnosis was facilitated*	**‘You have to fight so hard’: Barriers persisting across SMHS** **‘They say one thing, they do something else’: how experiences**	**‘Take it or leave it’: losing your voice in SMHS** *Psychiatrist refusing to change diagnosis or treatment* *Complaint led to a change in CPN*	**‘Feeling done to’: the illusion of power and control in SMHS** **‘It felt a little bit pointless’: expectations versus reality in SMHS**	**‘You get diagnosed and then you just get left’: The juxtaposition between expectations and reality** *Internalising things when you’re not listened to*	**‘I wasn't really surprised… just a little bit disappointed’: becoming dispirited in SMHS** *No choice in therapy*

	Autism diagnosis made SMHS treatment actionable *More consideration of needs with the autism diagnosis compared to the PD diagnosis prevalent across SMHS* *Contact was person centred and needs led* *Felt more listened to by care coordinator*	**erode trust in SMHS** *Limited information about choices* *Using own experience to seek diagnosis*		*ASC query came from own reading*		*Agreed to therapy because they didn't know there was other options* *Would have chosen the therapy they got if given the choice, but choice is important*

	following PD diagnosis					
Compassion Cultivates Compassion: Service and Individual Level Disparities in Care	**‘It’s more the people that have supported me’: individual relationships supersede service level experiences** *Interactions with crisis SMHS changed after PD diagnosis* *Feeling anger about the way they were treated*	**‘Oh, this is what good care looks like’: Trust, service, and individual level disparities in care** *Staff as offensive and stigmatizing*	**‘They were the only people on my side’; The impact of individuals within SMHS** *More compassion following ASC diagnosis*	*More compassion with ASC diagnosis* *Warm and validating responses with ASC* *SMHS should show compassion regardless of diagnosis* *There’s always good and bad attitudes*	*Kindness from understanding* *System letting people down* *Awful experiences in one Trust* *Therapists as brilliant* *Being treated kindly*	**‘It was like polar extremes’: experiences hinging on who is at the other side of them** *Unhelpful response was expected* *Negative experiences in SMHS echoed through other NHS services*

Understanding that some of the changes are due to SMHS changes and not the individual or diagnoses	*SMHS are too busy to support everyone*
	SMHS are invalidating
Contact with some service staff was mandatory	*Compassionate understanding about responses from SMHS*

Appendix 6

Distress Protocol

Identifying distress

- The participant indicates they are experiencing emotional distress or exhibits behaviours that suggests they are distressed such as crying, shaking etc.

Stage 1 support

- The researcher will pause the interview and the participant will be informed that they are able to withdraw at any time.
- The researcher will offer the participant opportunity to take a break or move onto a different topic.
- The researcher will use any support techniques that the participant identified as helpful during the introduction to the interview.
- If the participant feels able to carry on the interview will resume.
- Direct the participant to the support resources listed in the participant information sheet.
- If the participant feels unable to carry on go to stage 2.

Stage 2 Support

- Ask the participant if they would like to stop the interview (if no, return to phase 1).
- If the participant agrees that they would like the interview to stop, ask the participant if they would like to withdraw from the study or continue the interview at another time.
- Direct the participant to the support resources listed in the participant information sheet or approach their mental health team for support if recruited by NHS staff.

Appendix 7

Autism Reporting Guidelines

2.8 Reporting guidelines

2.8.1 Transparent reporting of trials

The relevant EQUATOR Network reporting guidelines should be followed depending on the type of study. For example, all randomized controlled trials submitted for publication should include a completed CONSORT flow chart as a cited figure and the completed CONSORT checklist should be uploaded with your submission as a supplementary file. Systematic reviews and meta-analyses should include the completed PRISMA flow chart as a cited figure and the completed PRISMA checklist should be uploaded with your submission as a supplementary file. The EQUATOR wizard can help you identify the appropriate guideline. The What Works Clearinghouse (WWC) guidelines should be followed when submitting in single-case design (SCD) and meet the standards outlined for internal validity of the SCD. Other resources can be found at NLM's Research Reporting Guidelines and Initiatives

2.8.2 Sample selection and demographic characteristics

Autism now requires authors to report the following information for all Research Reports (including systematic reviews):

i. procedures for sample selection and recruitment; and
ii. major demographic characteristics, including age, gender, race/ethnicity and socioeconomic status.

Including this information will provide greater clarity regarding sample characteristics and generalisability of the findings, even when such characteristics are not used in the analysis (although we encourage investigation of subgroup differences, where possible). It should also encourage researchers to consider the way in which context and culture contribute to their findings.

If authors are unable to report some or all of this information, its absence must be acknowledged with a clear statement of explanation (e.g., “specific data on socioeconomic status and educational attainment levels were not recorded”).

Manuscripts that contain neither the required information nor an appropriate statement will be returned prior to consideration by the editors.

2.8.3 Community involvement

Autism encourages research that is actively carried out ‘with’ or ‘by’ members of the Autistic and autism communities (rather than ‘to’, ‘about’, or ‘for’ them), often referred to as ‘co-production’, ‘participatory research’, ‘patient and public involvement’ or ‘integrated knowledge translation’.

We therefore now require authors to include a community involvement statement at the end of the Methods section for Research Reports, outlining whether autistic people or family members, community providers, policy makers, agency leaders or other community stakeholders were involved in developing the research question, study design, measures, implementation, or interpretation and dissemination of the findings. Community members should be duly acknowledged – as authors or in the acknowledgements section – depending on the extent and nature of their contribution. We recommend that authors follow the BMJ’s editorial guidelines for documenting how community stakeholders were involved in their research.

If community members were not involved in the study, authors should state this. For more details about the reasoning behind this journal requirement, and editorial expectations of authors, please download this FAQs document.

2.9 Data Policy Statement

Autism supports open research practices and FAIR principles. As such encourages authors to share their data wherever possible and submit their data (or a link to it) and where applicable, their syntax/command files for the analyses presented in the contribution. Authors can make data available through a third party data repository or on the journal website as a supplementary data file.

If cited data is restricted (e.g. classified, require confidentiality protections, were obtained under a non-disclosure agreement, or have inherent logistical constraints), authors should notify the editor at the time of submission. The editor shall have full discretion to follow their journal’s policy on restricted data, including declining to review the manuscript or granting an exemption with or without conditions. The editor shall inform the author of this decision prior to review.

Where data is sensitive and cannot be shared in an open forum, authors are encouraged to share metadata and provide a contact for requesting access if the raw data itself cannot be made available.

Data can be submitted with your article and hosted on the Sage Autism website where we work with Figshare to host data content. Authors can use a recognised third party data repository service to host their data such as Open Science framework. Authors may use their institution's data sharing repository.

Autism also encourages authors to delineate clearly the analytic procedures upon which their published claims rely, and where possible provide access to all relevant analytic materials. If such materials are not published with the article, we encourage authors to share to the greatest extent possible through a digital repository (above). Autism encourages authors to use data citation practices that identify a dataset's author(s), title, date, version, and a persistent identifier. In sum, data should be referenced and cited, where possible, as an intellectual product of value.

3. Publishing Policies

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This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc) alongside the full-text of the article. For more information please refer to our guidelines on submitting supplementary files.

4.4 Terminology

4.4.1 Terminology about autism and autistic people

Autism has researched and produced its own guidance on terminology and language used in autism research. Please consult the guide here: autism terminology guidelines.

4.4.2 Language used to discuss race and ethnicity

Likewise, Autism has also produced the following guidance to be considered when writing about race and ethnicity. Please consult the guide here: race and ethnicity language guidelines.

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Section Three: Critical Appraisal

Critical reflections on researching experiences of secondary mental health services from the perspective of autistic adults diagnosed with a personality disorder

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Critical Appraisal

The critical appraisal will provide a broad overview of the findings of the systematic literature review and the empirical paper, alongside in-depth, critical reflections of both papers and the research process. The strengths and limitations of each paper will be discussed, alongside clinical implications, future research, and the researcher's personal reflections.

Overview of Findings

A systematic review of the impact of attention deficit hyperactivity disorder (ADHD) or autism spectrum condition (ASC) in adulthood on mental health and wellbeing is presented within the first section of this thesis. Negative impacts on mental health and wellbeing were explored, alongside the protective factors that mitigate these impacts. The review outlined that participants' beliefs about diagnoses, changes in relationships with self and others, and seeing the past and future through a new lens were all experienced as salient factors affecting their mental health and wellbeing post-diagnosis by those diagnosed in adulthood. The review highlighted the phenomena that were experienced by the participants within the review that were linked to poor mental health and wellbeing: internalized stigma, identity threat, and regret and hopelessness. Participants described how stigma from others, non-disclosure, and lack of support contributed to these experiences, alongside the experiences post-diagnosis that had served to protect their mental health and wellbeing including improving their understanding about the diagnoses, feeling a sense of belonging, and having access to support and adaptations. Furthermore, timely diagnosis was hypothesised as a preventative measure against the impact of late diagnosis of ADHD or ASC.

The original research presented within the empirical paper in the second section of this thesis explored experiences of secondary mental health services (SMHS) from the lived experience of six adults who had been diagnosed with ASC following an initial diagnosis of a personality disorder (PD). Interpretative Phenomenological Analysis was used as the method of analysis within the paper, and the researcher took a critical realist stance; identifying that a reality outside of the human consciousness exists, whilst identifying that participants' lived experiences and the social structures that have influenced them makes the truth of their reality subjective (Tikly, 2015). These experiences focused on a sense of loss of individuality to a diagnostic label, the impact of stigma, expectations of SMHS not being met, the power of understanding the challenges associated with PD and/or ASC, and the impact of individuals within SMHS. The research highlighted the challenges this population can face within

SMHS, and how the diagnoses attached to them can influence and change these experiences. Participants reflected on where SMHS fall short of meeting the needs of autistic adults who are initially diagnosed or misdiagnosed with a PD, and shared their thoughts about what might have caused some of their challenging experiences.

Strengths, Limitations, and Suggestions for Future Research

Systematic Literature Review

The systematic review synthesised findings specific to the lived experience of adult diagnosis of ADHD or ASC in relation to its impact on mental health and wellbeing, a synthesis which has not previously been undertaken to the author's knowledge. The findings contributed to the development of a novel conceptualisation of the impacting and protective factors of diagnosis in adulthood in relation to mental health and wellbeing. Furthermore, the findings contributed to clinical recommendations regarding supporting those diagnosed with ADHD or ASC in adulthood within mental health services.

The review focused on adult diagnosis of both ADHD and ASC as both neurodevelopmental conditions have been identified as being associated with an upward trend in adult diagnosis within the UK (McKechnie et al., 2023; Russell et al., 2022). Additionally, ASC and ADHD frequently co-occur (Ghirardi et al., 2018; Leitner, 2014), and it is identified within the DSM-5 that ADHD symptoms are common in autistic individuals (American Psychiatric Association, 2013). With that in mind, it seemed important that the review considered both diagnoses, and that any recommendations resulting from the review were applicable across the diagnoses. Given the narrow focus of the review, focusing only on the impact of adult diagnosis on mental health and wellbeing, including one diagnosis would have greatly reduced the quantity and quality of information pertaining to lived experiences within the review. Whilst the impact of adult or late diagnosis of both diagnoses has been researched, the information pertaining to the impact on mental health and wellbeing specifically is limited.

For the purpose of the review, studies and results pertaining to self-diagnosed ADHD or ASC were excluded. There is a paucity of research exploring the accuracy of selfdiagnosis for both ADHD and ASC, and self-diagnoses are likely to be ignored by professionals (Lewis, 2017), therefore self-diagnosed adults would be unlikely to have access to the same post-diagnostic support as formally diagnosed adults. The impact of selfdiagnosis of ASC in adulthood has been explored, and the impact on mental health and wellbeing was largely linked to remaining without a formal diagnosis (Lewis, 2016). The impact of self-diagnosis of ADHD in adulthood has yet to be researched, to the author’s best knowledge. Therefore, it is uncertain whether this group would share the experiences of those formally diagnosed in adulthood, and therefore it felt appropriate to exclude them for the purposes of the review. However, it is acknowledged that this is an important group to consider regarding support within mental health services as there are documented impacts of self-diagnosis of ASC, and further research to include the experiences of adults who selfdiagnose with ADHD would be valuable.

The review does not include a breakdown of the demographics of the participants within the reviewed studies beyond which country the studies were conducted in, age ranges, and the genders of the participants. This was due to limited and varying demographic information across the studies, and as such demographics such as race, specific age, and any comorbid mental health conditions could not be reported on. This limits the review in its ability to identify who within the population of those diagnosed in adulthood is the most likely to be impacted post-diagnosis regarding mental health and wellbeing. This would be important information to capture as is could serve to highlight who the proposed clinical implications within the review should target. However, some data exists regarding who is most at risk of missed or late diagnosed ASC (Fusar-Poli et al., 2022) and ADHD (Schein et al., 2023) regarding mental health comorbidities.

Finally, the review only explored papers written in English, and the countries the studies were conducted it were predominantly western countries. As such, the findings and implications should not be generalized across non-western groups, and the experiences within the findings should not be interpreted as universal experiences across cultures.

Empirical Paper

The empirical paper added to a growing body of literature exploring late diagnosis of ASC from the unique perspective of individuals with an initial diagnosis of PD who have lived experiences of accessing SMHS. Whilst much of the existing literature investigating experiences of being diagnosed with ASC in adulthood acknowledges a lack of postdiagnostic support (Crane et al., 2018; Crowson et al., 2024), this study aimed to explore the experiences of those who were accessing services prior to their ASC diagnosis, and whether this new diagnosis changed their experiences of that support. The results highlighted an overlap between experiences post PD and post ASC diagnosis, including experiences of stigma and the perceived lack of knowledge and understanding of SMHS clinicians. The use of Interpretive Phenomenological Analysis (IPA) allowed the meaning each participant made of their unique yet similar experiences in SMHS to be drawn out and presented in themes that have meaningful implications for the future care of this group. The research provided the participants a voice, both to share their experiences of SMHS and to have their say in how services can improve. This feels important considering the experience of losing one's voice within SMHS that was described by the participants.

Whilst full participant demographics were not collected or recorded, it is acknowledged that the recruitment process made the research open to primarily western, English-speaking individuals with the economic means to access the internet. It is important to consider the experiences of those across cultures, and to explore cultural variations in experiences with SMHS, particularly as mental health services and stigma associated with diagnoses vary across cultures (Carpenter-Song et al., 2010). Gender identity was a further demographic that wasn't collected or reported for the purpose of the empirical paper. This is explored in more detail within the thesis and aimed to mitigate the risk of assumptions and knowledge about the relationship between diagnoses and genders being applied to the participants' experiences. Whilst there is a body of existing literature exploring gender, PD, and ASC (May et al., 2021; Rinaldi et al., 2021) it would be important to consider experiences of SMHS from the perspective of those with PD and late diagnosed ASC who are gender diverse.

The study aimed to interview between eight and twelve participants, with the final number of interviews totaling six. Whilst this fell short of the recruitment aim, it was sufficient in achieving rich accounts, and reached theoretical sufficiency. It is important that IPA research highlights the individual accounts of lived experiences alongside identifying commonalities across a small, homogenous sample (Larkin et al., 2021). The sample was homogenous in that all participants had the shared experience of being diagnosed with a PD prior to being diagnosed with ASC, and of accessing SMHS. It is acknowledged that there were varying timeframes between PD and ASC diagnosis across the sample, however the order of receiving each diagnosis was the pertinent factor within the research. It could be argued that given the varying gaps between diagnoses, participants with the longer periods since PD diagnosis may have struggled to recall SMHS experiences post PD diagnosis. However, it is suggested that this did not impact the richness of the accounts as all participants gave considerable weight to their time under SMHS with a PD diagnosis. Additionally, some participants included accounts of other comorbidities including mental and physical health diagnoses, acknowledging their impact on their experiences. Whilst this was not explored within the empirical paper, it is important to consider the impact of diagnoses other than PD for those diagnosed with ASC in adulthood.

Finally, consideration was given to the mediums through which interviews were held. It was decided that interviews would be offered via MSTeams or telephone, with face-to-face interviews being offered to those recruited via NHS SMHS within agreed NHS sites. Whilst this provided participants with some choice, their preferred method of communication may not have been available to them. Having choice over how autistic individuals engage with research has been found to be a common enabler for autistic people participating in research (Haas et al., 2016). Whilst some choice was given, perhaps not restricting the participants to a limited number of options would have been more beneficial in encouraging engagement. Examples such as completing qualitative surveys are discussed within the empirical paper.

Clinical Implications

The findings of both the systematic literature review and the empirical paper suggest that mental health services could be an appropriate support system for those diagnosed with

ASC or ADHD in adulthood. Post-diagnostic support was perceived as important yet difficult to access by the participants across the two papers. Whilst specific support for neurodivergent adults may be viewed as the role of neurodevelopmental services, both papers suggest possible clinical implications relevant to primary and secondary mental health services. This was further supported by one participant within the empirical study, who identified that awareness of how to work with autistic adults is important within SMHS given they are commonly supported by the services: "considering a lot of the time neurodivergent patients get seen through mental health services, I would have assumed you've had something or that it's additional training that you have as part of your regular training" (P2).

Participants across the two papers explored their experiences of stigma in relation to diagnostic labels and how these experiences had impacted their mental health, wellbeing, and perception of mental health services. As increasing knowledge has been observed to be more effective at reducing stigma than interventions targeting stigma (Kentrou et al., 2021), staff support and training around working with neurodivergent adults is suggested. The Oliver McGowan Mandatory Training on Learning Disability and Autism is the preferred training for health and social care staff working with autistic individuals (NHS England, 2024) and aims to reduce health inequalities through upskilling staff to provide appropriately adjusted care for autistic people. There are currently no NHS recommended training or education packages for mental health professionals working with adults with ADHD. This suggests a gap in mental health professionals' training that needs to be addressed as a component of working towards providing mental health and wellbeing support to adults with ADHD post diagnosis.

The effects of adult diagnosis being perceived as late or missed diagnosis were apparent across both papers. Feelings of anger, sadness, and guilt were expressed by participants and calls were made for more timely diagnosis to prevent some of the challenging experiences associated with being undiagnosed. Fear of not being believed by professionals has been highlighted as a barrier to accessing formal diagnosis for autistic adults (Lewis, 2017). As the empirical paper highlights, not being believed by professionals was a challenge that the participants described when they were accessing SMHS with a PD diagnosis, suggesting this population may be at increased risk of feeling unable to access formal diagnosis. Reasonable adjustment requests should be considered by SMHS regardless of formal diagnosis. Participants within the empirical paper commented on the benefits of their needs that they associated with being autistic being met prior to formal diagnosis, and this would promote neuro-affirmative practice withing SMHS by holding consideration for neurodiversity amongst all staff and service users regardless of whether they are neurodivergent.

Gender was explored by some of the participants within the empirical paper as a potential barrier to receiving a timely autism diagnosis, specifically for females. Ratios for male:female ASC diagnosis have been observed to be around 3:1 (Loomes et al., 2017) which has been attributed to factors including the possibility of a female ASC phenotype that is typically unrecognized within the current conceptualization of ASC (Rubenstein et al., 2015). Clinician bias has been observed as a barrier to female ASC diagnosis (Lockwood Estrin et al., 2021), with females typically being diagnosed with other conditions despite evidence of ASC being documented in clinical records. Increased masking in females has been posited as one potential explanation for this bias (Milner et al., 2019), highlighting the need for better understanding of this phenomenon to improve the timeliness of diagnosis in females. Tools to aid in the identification and understanding of masking have been developed (Hull et al., 2019; Livingston et al., 2020) and may be beneficial within SMHS to assist in differentiating ASC from commonly misdiagnosed mental health difficulties such as PD.

Personal Reflections

My experiences working within SMHS, specifically acute inpatient and a Complex Emotional Needs service, inspired the development of the empirical research. Within my previous roles I had observed the challenges that people diagnosed with a PD faced in SMHS, and the growing number of those who were beginning to be diagnosed with ASC. It became apparent that this was a growing population whose experiences of SMHS would be important to understand to help shape the future of SMHS. This is particularly important given that the National Quality Board highlights coproduction and responding to feedback as two of three key principles in delivering the best experiences in care systems (NHS England, 2022).

I was aware throughout the research process that my own experiences, opinions, and biases may impact the research, and was mindful to keep a log of my thoughts and experiences throughout to ensure they did not impact my analysis or results. An excerpt from my reflective log below highlights my reactions to Participant 1's interview:

> "I noticed feelings of anger during Participant1's account of their experiences in SMHS, and I am mindful that anger is my response to what I have heard, not something they communicated that they felt in response to their experiences, and therefore should not be reflected within the analysis of their interview".

Keeping a log of these experiences allowed me to separate my own experiences hearing about the challenges participants faced within SMHS from how they perceived, responded to, and understood them. This allowed me to ensure my reactions and responses did not impact the analysis process.

Listening to participants' accounts of their experiences in SMHS encouraged me to reflect on my position within these systems and my values moving forward into my future qualified role within the NHS. I reflected on how I might fit into a system which can be challenging for the people it is designed to support, including through perpetuating stigma and invalidation:

> "I hope to work in a service that supports individuals with complex emotional needs, including those who may attract a PD diagnosis post qualification, and today's interview has left me wondering how I will position myself within systems that can be harmful. The importance of compassion towards the challenges both the people I will be supporting and the people I will be working alongside feels important." This has fostered a growing interest in compassionate approaches including compassionate leadership (Cole-King & Gilbert, 2014) and how these approaches can be adopted by clinical psychologist to promote compassionate care within SMHS.

I found conducting the interviews challenging, not in the process of interviewing via MSTeams or through using semi-structured interviews, but rather the emotive nature of the content of the interviews and my own pull to validate and reassure the participants. Validation is an important part of providing compassionate care, as compassion itself if defined as noticing suffering and being committed to doing something about it, which requires that the suffering is validated at some level. The experience of moving between the roles of a trainee clinical psychologist as a therapist and a researcher and the challenges associated with this do not appear to have been investigated. It would be interesting to explore whether this was a common challenge when completing qualitative research.

Throughout the research I kept a keen eye on what the common social discourses around the increase in diagnoses of neurodevelopmental (ND) conditions were, primarily through social media including Twitter (X). I observed a number of prominent public figures invalidating ND diagnoses as behavioural problems or products of modern living including over reliance on technology. I found these evaluations of neurodivergent individuals challenging to read, noticing feelings of anger and frustration, and reflected on how common social discourses around ND diagnoses may have impacted the participants within my study. This would perhaps be an interesting piece of future research, as social media has been shown to influence the perception of ASC as observed through analysis of public discourse on

YouTube video comments, including influencing stigma (Bakombo et al., 2023).

Before beginning recruitment for the empirical study, I had anticipated that I would easily recruit between eight and twelve participants due to the growing population of adults being diagnosed with ASC following a PD diagnosis. However, recruitment was challenging and ended before I hit my original minimum number of participants. Research exploring the impact of speaking about trauma from the perspective of trauma survivors indicates that sharing traumatic experiences can be both empowering and triggering (Taylor & Clarence, 2021). The distress protocol within the present study (appendix X) alongside the introduction to the interview each participant received (appendix X) aimed to mitigate this risk, however it is still possible that the retelling of their experiences in SMHS was traumatic or challenging for the participants. Participants were engaged in conversation at the end of each interview including being given an option to ask any questions and a wellbeing check in, which did not indicate any distress following the interviews, however a quantitative measure of distress may have been helpful to have considered as a post-interview activity.

In seeking ethical approval for the study I was required to attend a Research Ethics Committee (REC) review to answer any questions about my ethics application. I was surprised to hear a reflection within the review that resulted in my initial plan to recruit via social media being rejected (later approved following an amendment). It was suggested that potential participants may lie about having a formal diagnosis of ASC to enable them to be involved in the research. I did not challenge this within the review, perhaps due to anxiety, however I wondered whether this reflected the stigma that is associated with individuals who attract diagnoses of PD. As identified within the empirical paper, it was not unusual for participants to hear words like ‘manipulative’ or ‘attention seeking’ being used to describe them: “I think they made out everything I was doing was attention seeking” (P3). This experience reaffirmed the importance of this research and its aims to give a voice to the lived experiences of a population who are frequently subjected to treatment influenced by stigma, and to suggest ways to move forward that will make experiences of accessing SMHS less challenging.

Finally, it felt poignant during analysis that compassion for SMHS and why they may be challenging came through within the participants accounts within the empirical paper. This stood out to me as across the accounts compassion seemed to be missing from participants’ interactions with SMHS, particularly following PD diagnosis. It would be important to consider what has influenced this compassion, and how this knowledge could be transferred to SMHS staff who commonly experience compassion fatigue (Ray et al., 2013).

Conclusion

This thesis was a product of my own experiences working with SMHS and observing how they can be challenging for the growing population of adults diagnosed with a PD who are later diagnosed with ASC. It was motivated by a passion to improve SMHS for this population, and to give them an opportunity to share their experiences and thoughts for moving forward in the development of more compassionate systems within the NHS. I hope this research can contribute to meaningful change, and I hope to see more compassionate, trauma informed services in the future, which I will continue to influence within my work as a qualified clinical psychologist.

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Section Four: Ethics Proposal

Ethics proposal for the empirical study: Experiences of individuals with a diagnosis of Personality Disorder being diagnosed with Autism Spectrum Condition whilst in secondary mental health services

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Word count (excluding references, tables, and appendices): 3835

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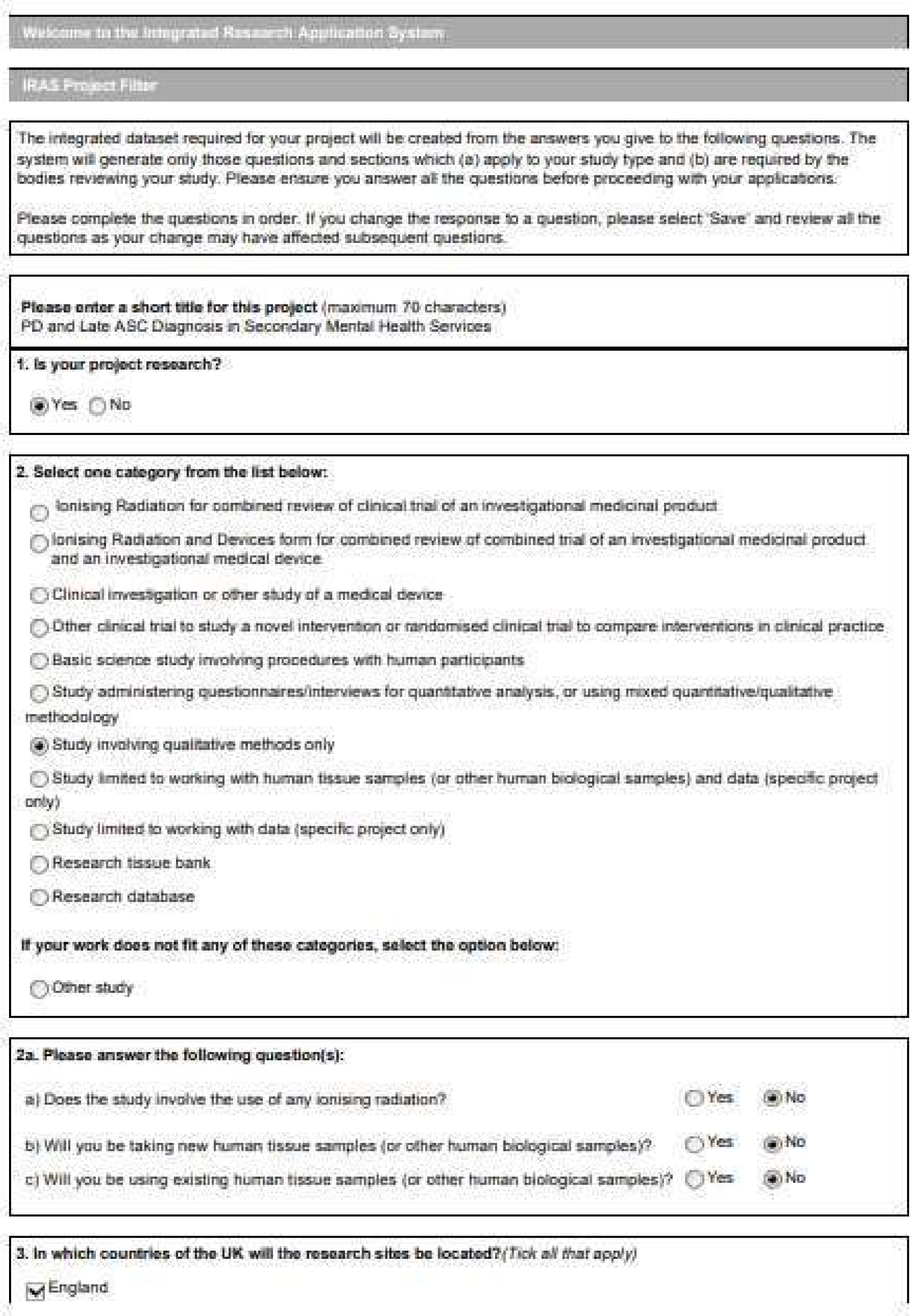
Integrated Research Application System (IRAS)

Application for Ethical Approval



Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please complete the questions in order. If you change the response to a question, please select 'Save' and review all the questions as your change may have affected subsequent questions.

Please enter a short title for this project (maximum 70 characters)
PD and Late ASC Diagnosis in Secondary Mental Health Services

1. Is your project research?

● Yes ○ No

2. Select one category from the list below:

○ Ionising Radiation for combined review of clinical trial of an investigational medicinal product
○ Ionising Radiation and Devices form for combined review of combined trial of an investigational medicinal product and an investigational medical device
○ Clinical investigation or other study of a medical device
○ Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice
○ Basic science study involving procedures with human participants
○ Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology
● Study involving qualitative methods only
○ Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)
○ Study limited to working with data (specific project only)
○ Research tissue bank
○ Research database

If your work does not fit any of these categories, select the option below:

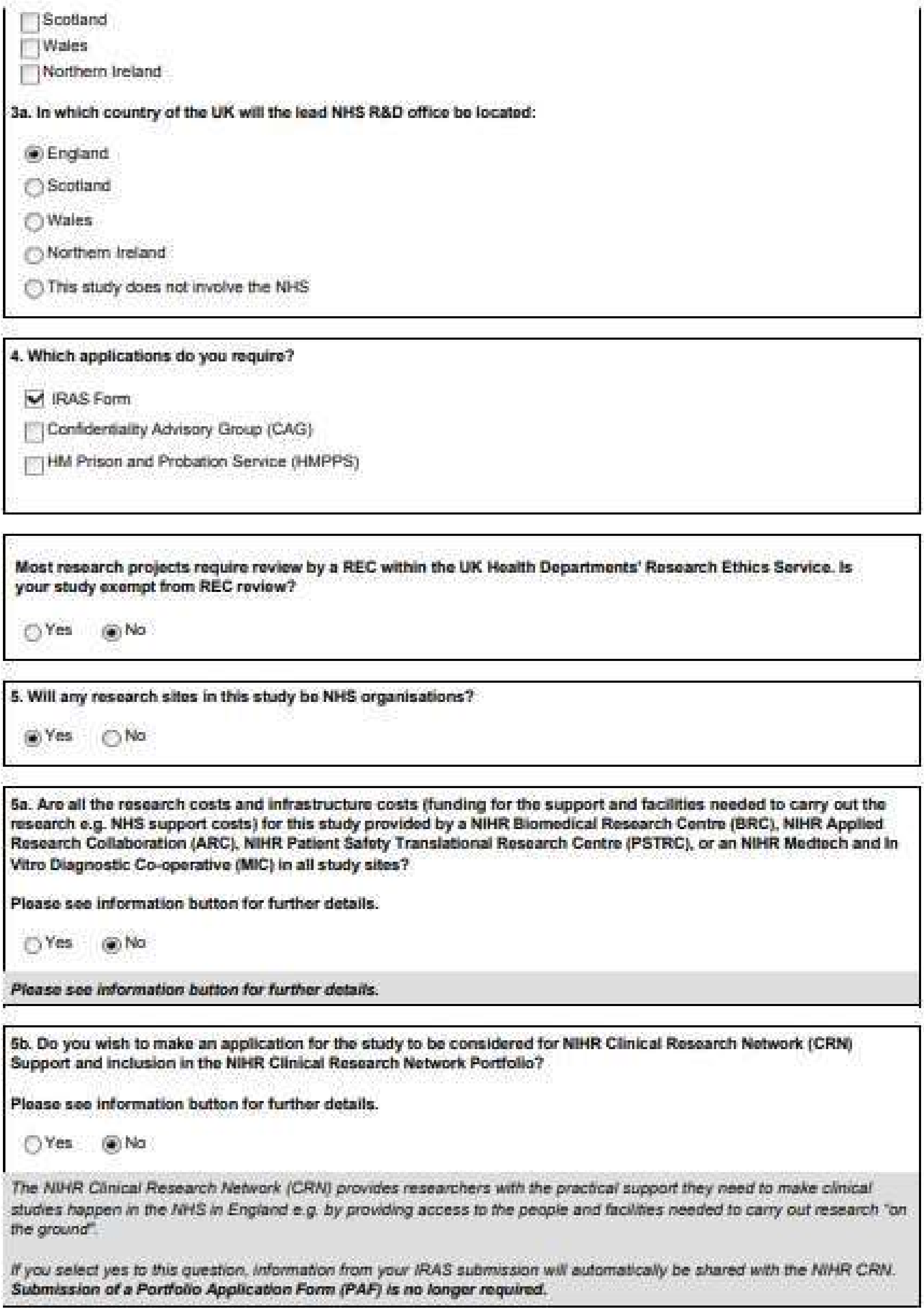
○ Other study

2a. Please answer the following question(s):

a) Does the study involve the use of any ionising radiation?	○ Yes	● No
b) Will you be taking new human tissue samples (or other human biological samples)?	○ Yes	● No
c) Will you be using existing human tissue samples (or other human biological samples)?	○ Yes	● No

3. In which countries of the UK will the research sites be located?*(Tick all that apply)*

☑ England



☐ Scotland
☐ Wales
☐ Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

● England
○ Scotland
○ Wales
○ Northern Ireland
○ This study does not involve the NHS

4. Which applications do you require?

☑ IRAS Form
☐ Confidentiality Advisory Group (CAG)
☐ HM Prison and Probation Service (HMPPS)

Most research projects require review by a REC within the UK Health Departments' Research Ethics Service. Is your study exempt from REC review?

○ Yes ● No

5. Will any research sites in this study be NHS organisations?

● Yes ○ No

5a. Are all the research costs and infrastructure costs (funding for the support and facilities needed to carry out the research e.g. NHS support costs) for this study provided by a NIHR Biomedical Research Centre (BRC), NIHR Applied Research Collaboration (ARC), NIHR Patient Safety Translational Research Centre (PSTRC), or an NIHR Medtech and In Vitro Diagnostic Co-operative (MIC) in all study sites?

Please see information button for further details.

○ Yes ● No

Please see information button for further details.

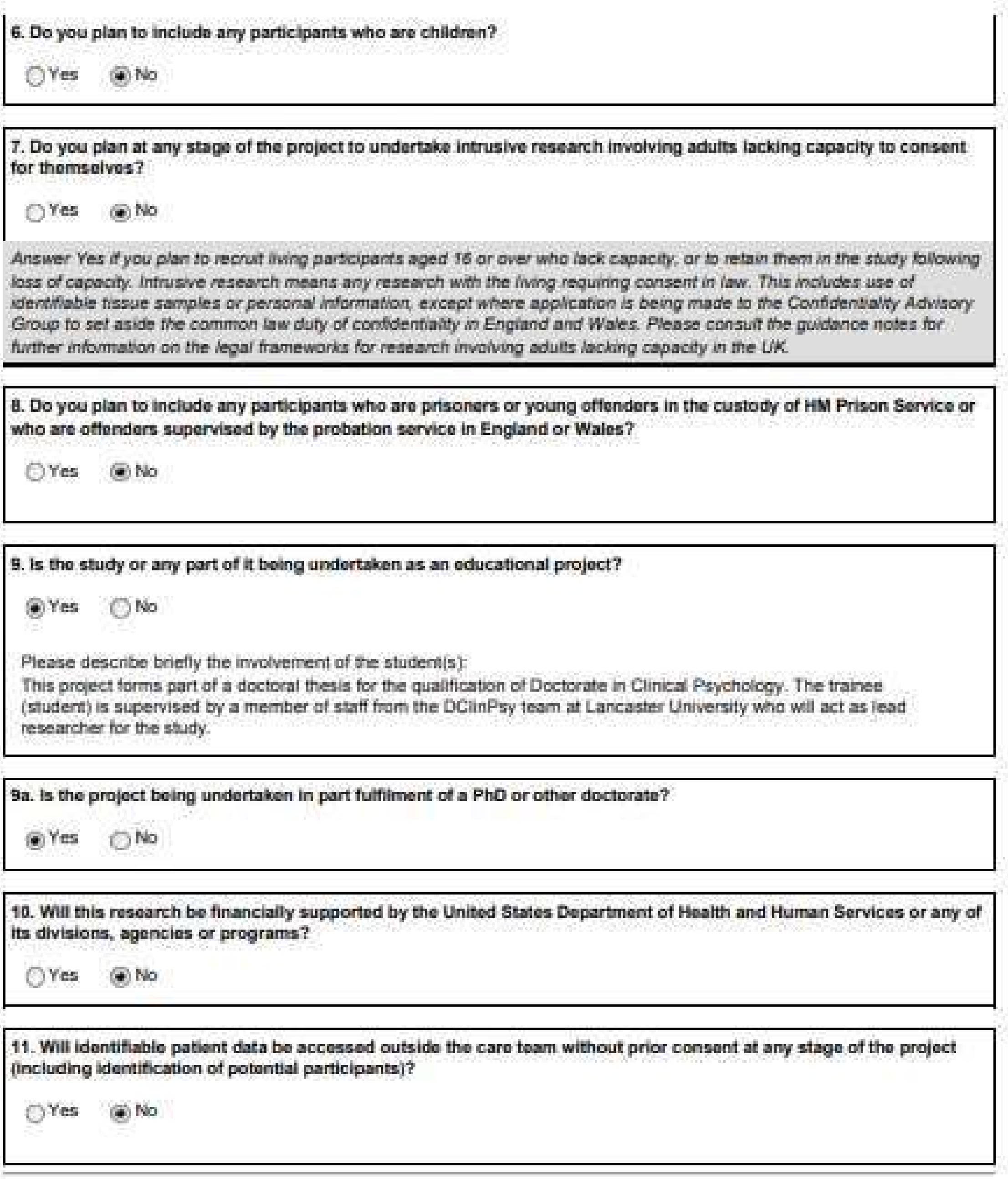
5b. Do you wish to make an application for the study to be considered for NIHR Clinical Research Network (CRN) Support and inclusion in the NIHR Clinical Research Network Portfolio?

Please see information button for further details.

○ Yes ● No

The NIHR Clinical Research Network (CRN) provides researchers with the practical support they need to make clinical studies happen in the NHS in England e.g. by providing access to the people and facilities needed to carry out research "on the ground".

If you select yes to this question, information from your IRAS submission will automatically be shared with the NIHR CRN. ***Submission of a Portfolio Application Form (PAF) is no longer required.***



6. Do you plan to include any participants who are children?

○ Yes ● No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

○ Yes ● No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the Confidentiality Advisory Group to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

○ Yes ● No

9. Is the study or any part of it being undertaken as an educational project?

● Yes ○ No

Please describe briefly the involvement of the student(s):
This project forms part of a doctoral thesis for the qualification of Doctorate in Clinical Psychology. The trainee (student) is supervised by a member of staff from the DClinPsy team at Lancaster University who will act as lead researcher for the study.

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

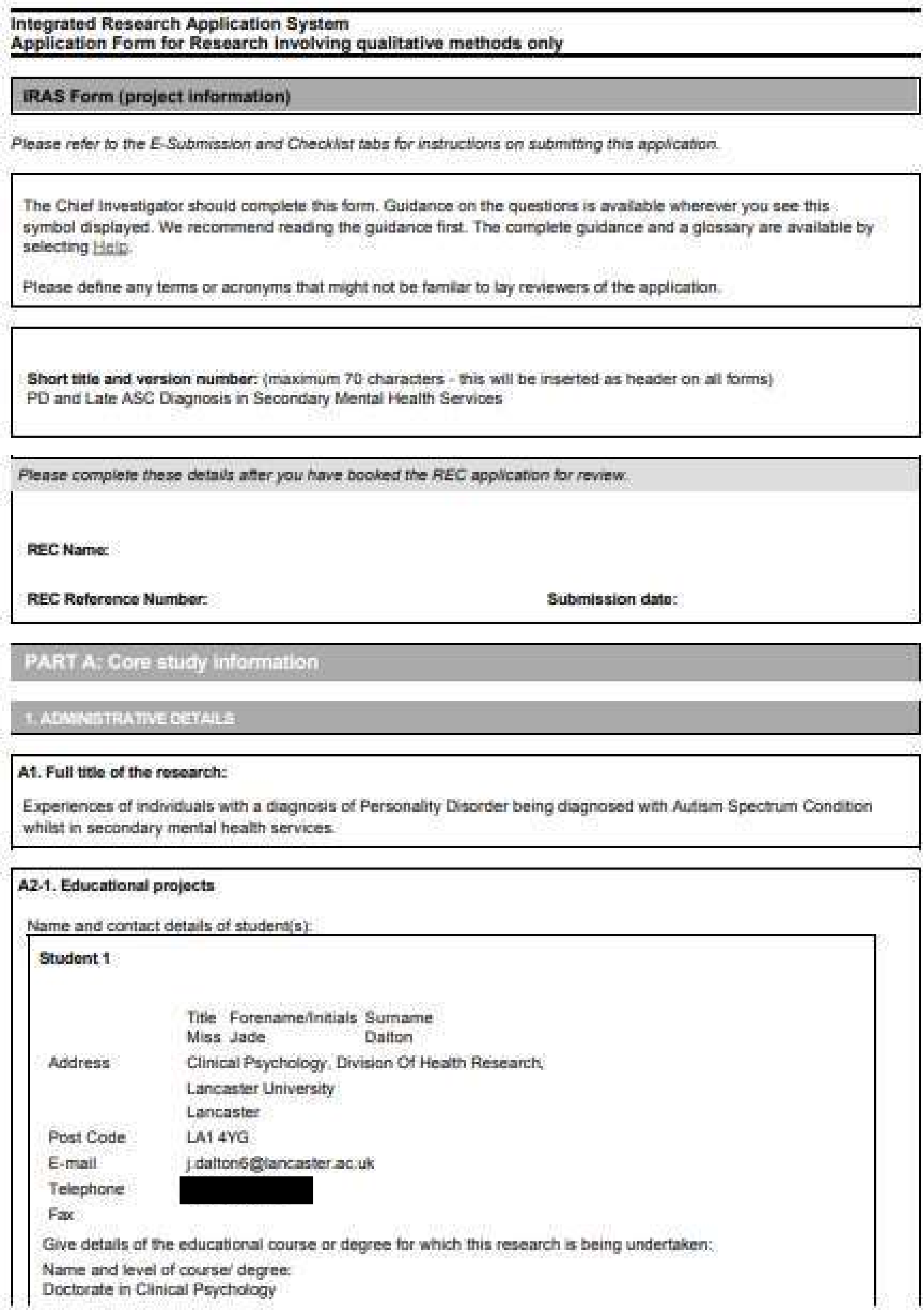
● Yes ○ No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

○ Yes ● No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

○ Yes ● No



Integrated Research Application System
Application Form for Research involving qualitative methods only

IRAS Form (project information)

Please refer to the E-Submission and Checklist tabs for instructions on submitting this application.

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting Help.

Please define any terms or acronyms that might not be familar to lay reviewers of the application.

Short title and version number: (maximum 70 characters - this will be inserted as header on all forms)
PD and Late ASC Diagnosis in Secondary Mental Health Services

Please complete these details after you have booked the REC application for review.

REC Name:

REC Reference Number: **Submission date:**

PART A: Core study information

1. ADMINISTRATIVE DETAILS

A1. Full title of the research:

Experiences of individuals with a diagnosis of Personality Disorder being diagnosed with Autism Spectrum Condition whilst in secondary mental health services.

A2-1. Educational projects

Name and contact details of student(s):

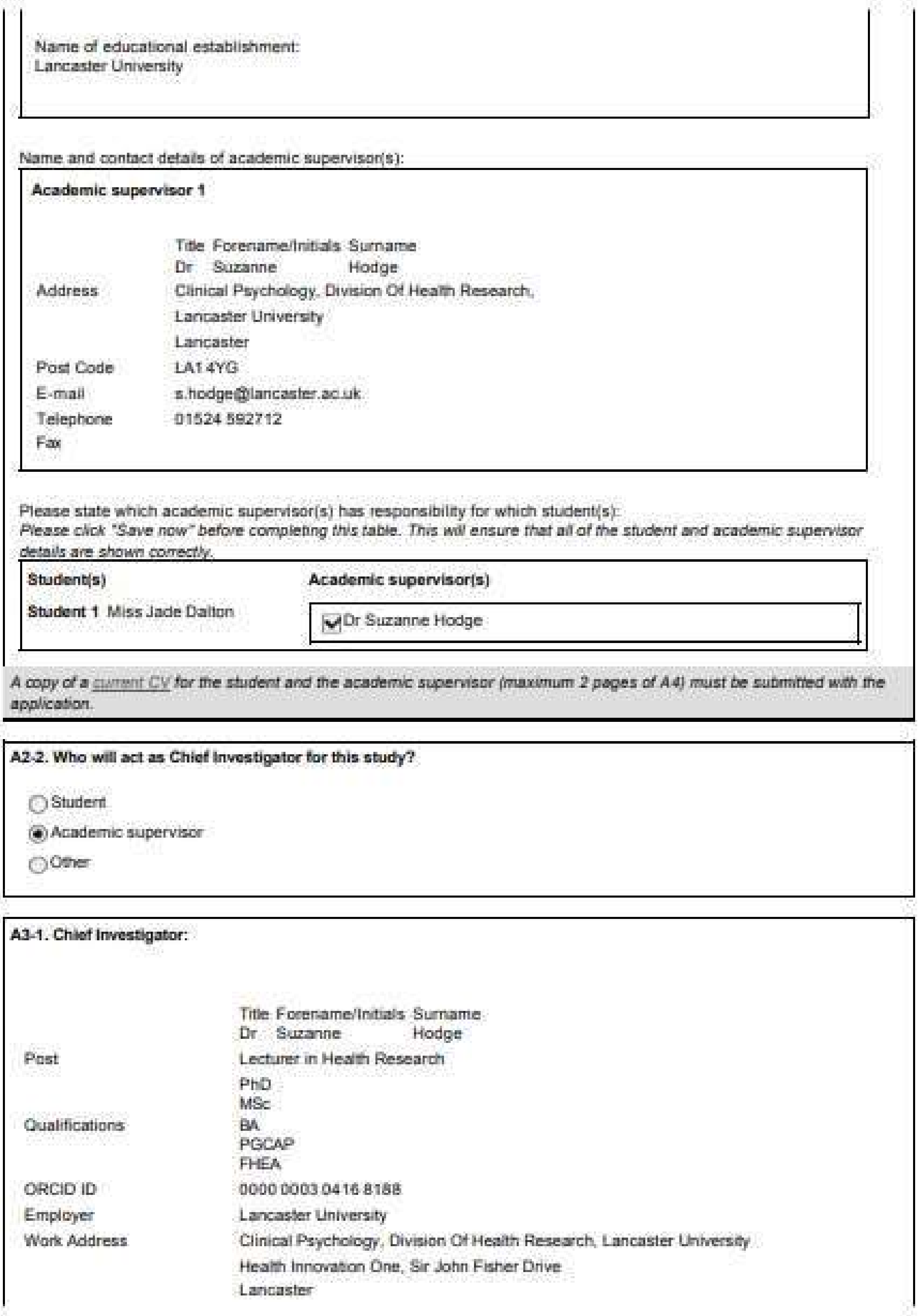
Student 1

	Title	Forename/Initials	Surname
	Miss	Jade	Dalton

Address Clinical Psychology, Division Of Health Research,
Lancaster University
Lancaster
Post Code LA1 4YG
E-mail j.dalton6@lancaster.ac.uk
Telephone [redacted]
Fax

Give details of the educational course or degree for which this research is being undertaken:

Name and level of course/ degree:
Doctorate in Clinical Psychology



Name of educational establishment:
Lancaster University

Name and contact details of academic supervisor(s):

Academic supervisor 1

	Title	Forename/Initials	Surname
	Dr	Suzanne	Hodge

Address Clinical Psychology, Division Of Health Research,
Lancaster University
Lancaster
Post Code LA1 4YG
E-mail s.hodge@lancaster.ac.uk
Telephone 01524 592712
Fax

Please state which academic supervisor(s) has responsibility for which student(s):
Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.

Student(s)	**Academic supervisor(s)**
Student 1 Miss Jade Dalton	☑ Dr Suzanne Hodge

A copy of a current CV for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.

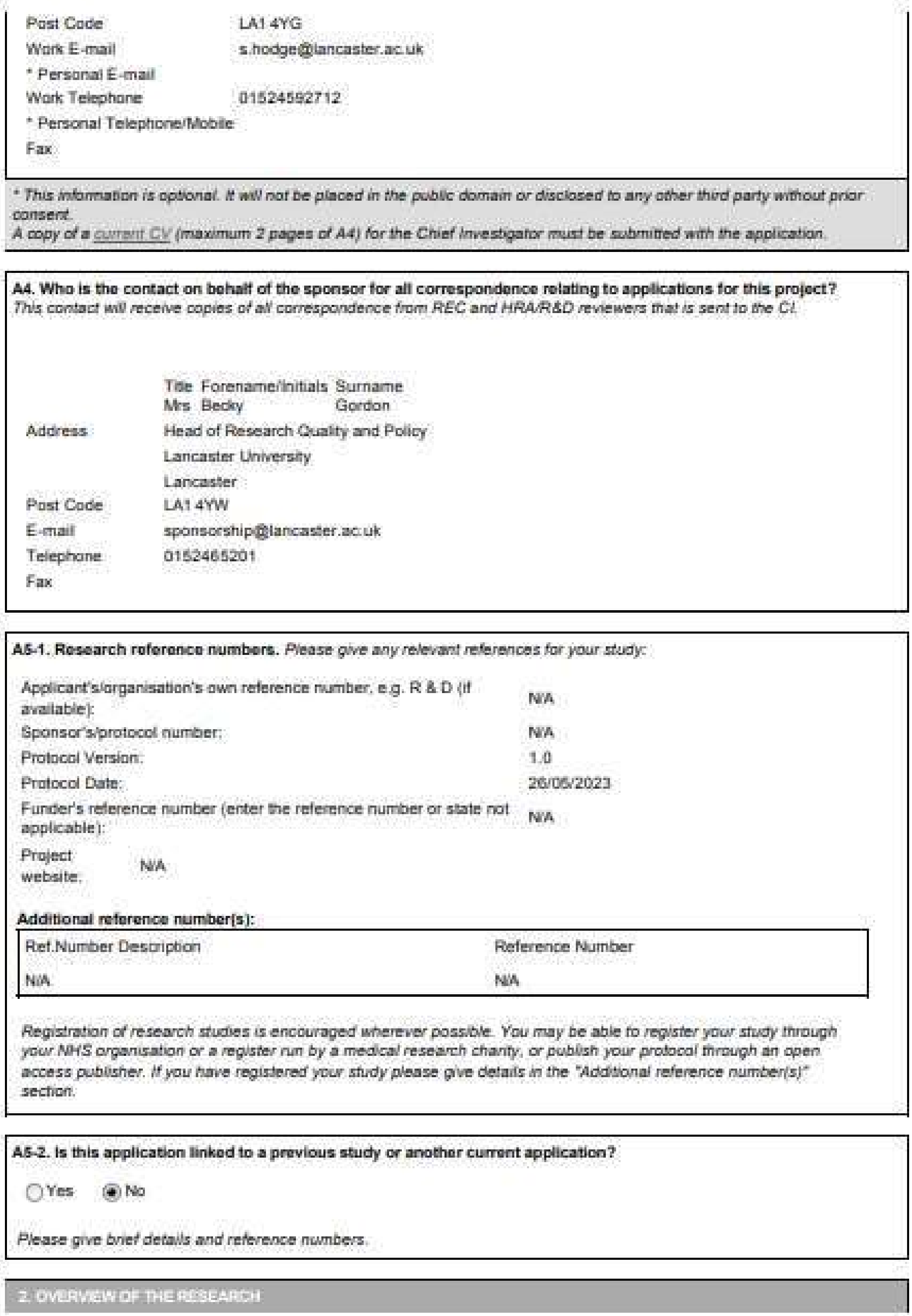
A2-2. Who will act as Chief Investigator for this study?

○ Student
● Academic supervisor
○ Other

A3-1. Chief Investigator:

	Title	Forename/Initials	Surname
	Dr	Suzanne	Hodge

Post Lecturer in Health Research
Qualifications PhD
MSc
BA
PGCAP
FHEA
ORCID ID 0000 0003 0416 8188
Employer Lancaster University
Work Address Clinical Psychology, Division Of Health Research, Lancaster University
Health Innovation One, Sir John Fisher Drive
Lancaster



Post Code	LA1 4YG
Work E-mail	s.hodge@lancaster.ac.uk
* Personal E-mail	
Work Telephone	01524592712
* Personal Telephone/Mobile	
Fax	

** This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.*
A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.

A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?
This contact will receive copies of all correspondence from REC and HRA/R&D reviewers that is sent to the CI.

Title	Forename/Initials	Surname
Mrs	Becky	Gordon

Address
Head of Research Quality and Policy
Lancaster University
Lancaster

Post Code	LA1 4YW
E-mail	sponsorship@lancaster.ac.uk
Telephone	0152465201
Fax	

A5-1. Research reference numbers. *Please give any relevant references for your study:*

Applicant's/organisation's own reference number, e.g. R & D (if available):	N/A
Sponsor's/protocol number:	N/A
Protocol Version:	1.0
Protocol Date:	26/06/2023
Funder's reference number (enter the reference number or state not applicable):	N/A
Project website:	N/A

Additional reference number(s):

Ref.Number Description	Reference Number
N/A	N/A

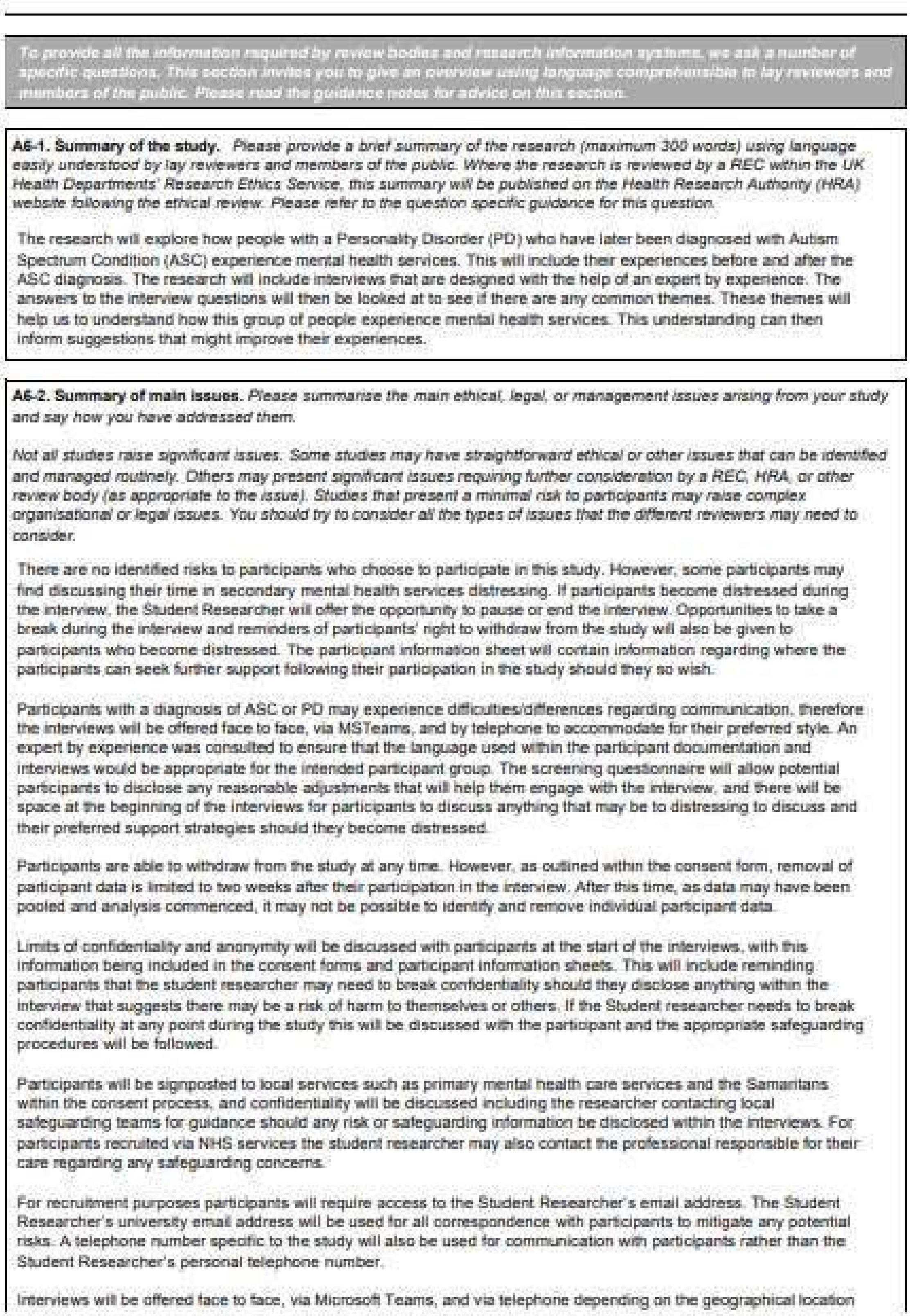
Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you have registered your study please give details in the "Additional reference number(s)" section.

A5-2. Is this application linked to a previous study or another current application?

○ Yes ● No

Please give brief details and reference numbers.

2. OVERVIEW OF THE RESEARCH



To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.

A6-1. Summary of the study. *Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments' Research Ethics Service, this summary will be published on the Health Research Authority (HRA) website following the ethical review. Please refer to the question specific guidance for this question.*

The research will explore how people with a Personality Disorder (PD) who have later been diagnosed with Autism Spectrum Condition (ASC) experience mental health services. This will include their experiences before and after the ASC diagnosis. The research will include interviews that are designed with the help of an expert by experience. The answers to the interview questions will then be looked at to see if there are any common themes. These themes will help us to understand how this group of people experience mental health services. This understanding can then inform suggestions that might improve their experiences.

A6-2. Summary of main issues. *Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.*

Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, HRA, or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.

There are no identified risks to participants who choose to participate in this study. However, some participants may find discussing their time in secondary mental health services distressing. If participants become distressed during the interview, the Student Researcher will offer the opportunity to pause or end the interview. Opportunities to take a break during the interview and reminders of participants' right to withdraw from the study will also be given to participants who become distressed. The participant information sheet will contain information regarding where the participants can seek further support following their participation in the study should they so wish.

Participants with a diagnosis of ASC or PD may experience difficulties/differences regarding communication, therefore the interviews will be offered face to face, via MSTeams, and by telephone to accommodate for their preferred style. An expert by experience was consulted to ensure that the language used within the participant documentation and interviews would be appropriate for the intended participant group. The screening questionnaire will allow potential participants to disclose any reasonable adjustments that will help them engage with the interview, and there will be space at the beginning of the interviews for participants to discuss anything that may be to distressing to discuss and their preferred support strategies should they become distressed.

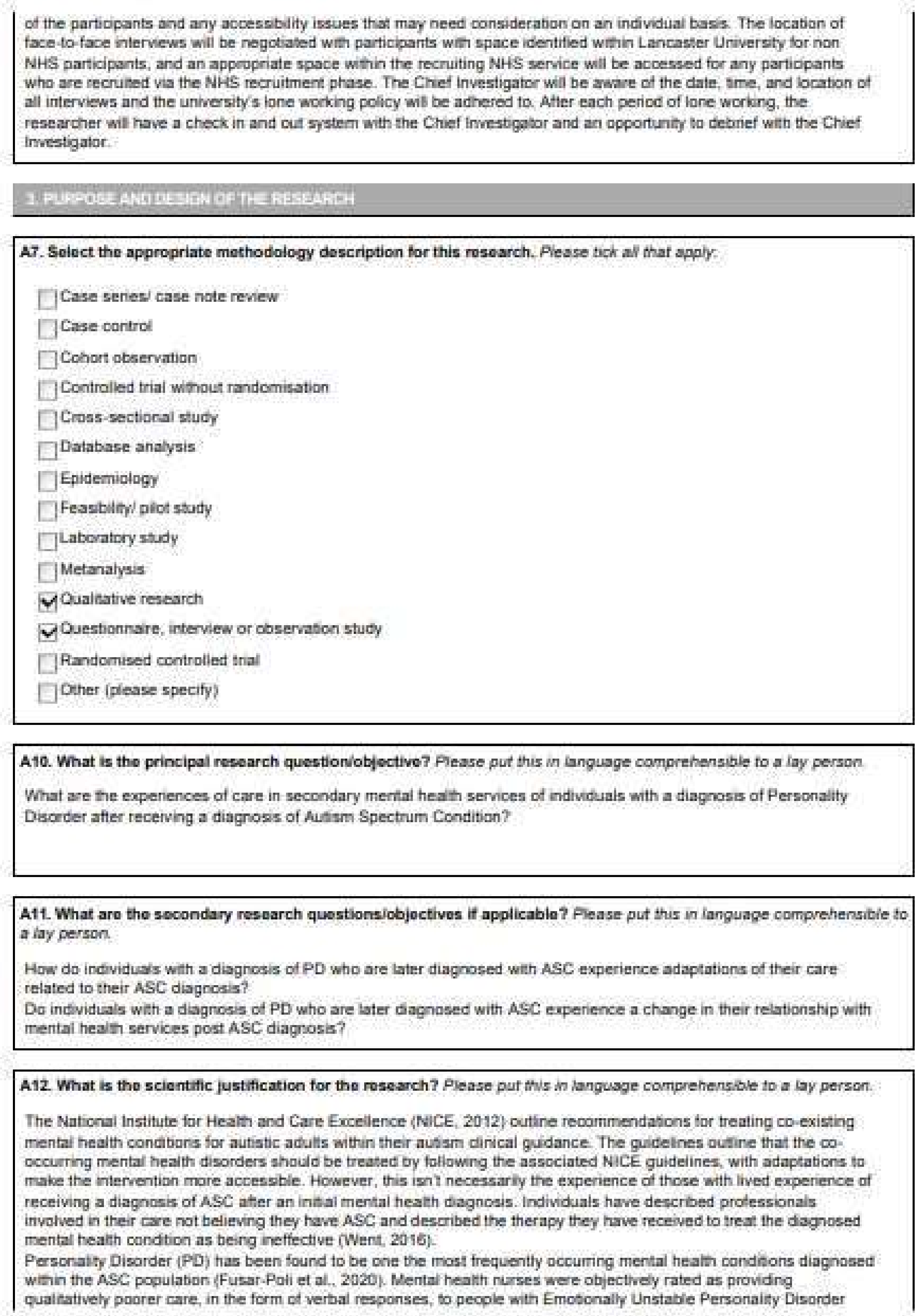
Participants are able to withdraw from the study at any time. However, as outlined within the consent form, removal of participant data is limited to two weeks after their participation in the interview. After this time, as data may have been pooled and analysis commenced, it may not be possible to identify and remove individual participant data.

Limits of confidentiality and anonymity will be discussed with participants at the start of the interviews, with this information being included in the consent forms and participant information sheets. This will include reminding participants that the student researcher may need to break confidentiality should they disclose anything within the interview that suggests there may be a risk of harm to themselves or others. If the Student researcher needs to break confidentiality at any point during the study this will be discussed with the participant and the appropriate safeguarding procedures will be followed.

Participants will be signposted to local services such as primary mental health care services and the Samaritans within the consent process, and confidentiality will be discussed including the researcher contacting local safeguarding teams for guidance should any risk or safeguarding information be disclosed within the interviews. For participants recruited via NHS services the student researcher may also contact the professional responsible for their care regarding any safeguarding concerns.

For recruitment purposes participants will require access to the Student Researcher's email address. The Student Researcher's university email address will be used for all correspondence with participants to mitigate any potential risks. A telephone number specific to the study will also be used for communication with participants rather than the Student Researcher's personal telephone number.

Interviews will be offered face to face, via Microsoft Teams, and via telephone depending on the geographical location



of the participants and any accessibility issues that may need consideration on an individual basis. The location of face-to-face interviews will be negotiated with participants with space identified within Lancaster University for non NHS participants, and an appropriate space within the recruiting NHS service will be accessed for any participants who are recruited via the NHS recruitment phase. The Chief Investigator will be aware of the date, time, and location of all interviews and the university's lone working policy will be adhered to. After each period of lone working, the researcher will have a check in and out system with the Chief Investigator and an opportunity to debrief with the Chief Investigator.

3. PURPOSE AND DESIGN OF THE RESEARCH

A7. Select the appropriate methodology description for this research. *Please tick all that apply:*

☐ Case series/ case note review
☐ Case control
☐ Cohort observation
☐ Controlled trial without randomisation
☐ Cross-sectional study
☐ Database analysis
☐ Epidemiology
☐ Feasibility/ pilot study
☐ Laboratory study
☐ Metanalysis
☑ Qualitative research
☑ Questionnaire, interview or observation study
☐ Randomised controlled trial
☐ Other (please specify)

A10. What is the principal research question/objective? *Please put this in language comprehensible to a lay person.*

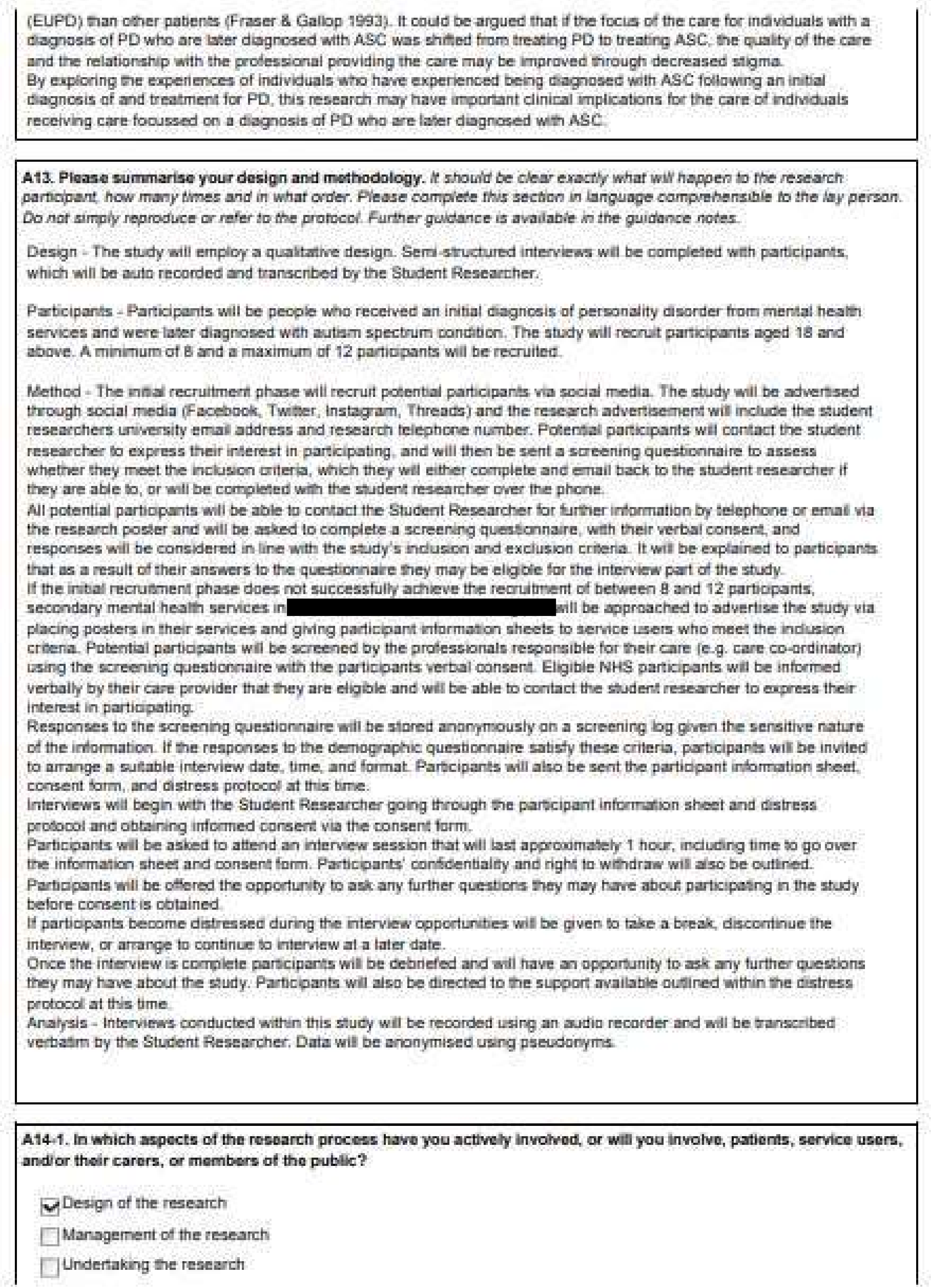
What are the experiences of care in secondary mental health services of individuals with a diagnosis of Personality Disorder after receiving a diagnosis of Autism Spectrum Condition?

A11. What are the secondary research questions/objectives if applicable? *Please put this in language comprehensible to a lay person.*

How do individuals with a diagnosis of PD who are later diagnosed with ASC experience adaptations of their care related to their ASC diagnosis?
Do individuals with a diagnosis of PD who are later diagnosed with ASC experience a change in their relationship with mental health services post ASC diagnosis?

A12. What is the scientific justification for the research? *Please put this in language comprehensible to a lay person.*

The National Institute for Health and Care Excellence (NICE, 2012) outline recommendations for treating co-existing mental health conditions for autistic adults within their autism clinical guidance. The guidelines outline that the co-occurring mental health disorders should be treated by following the associated NICE guidelines, with adaptations to make the intervention more accessible. However, this isn't necessarily the experience of those with lived experience of receiving a diagnosis of ASC after an initial mental health diagnosis. Individuals have described professionals involved in their care not believing they have ASC and described the therapy they have received to treat the diagnosed mental health condition as being ineffective (Went, 2016).
Personality Disorder (PD) has been found to be one the most frequently occurring mental health conditions diagnosed within the ASC population (Fusar-Poli et al., 2020). Mental health nurses were objectively rated as providing qualitatively poorer care, in the form of verbal responses, to people with Emotionally Unstable Personality Disorder



(EUPD) than other patients (Fraser & Gallop 1993). It could be argued that if the focus of the care for individuals with a diagnosis of PD who are later diagnosed with ASC was shifted from treating PD to treating ASC, the quality of the care and the relationship with the professional providing the care may be improved through decreased stigma.
By exploring the experiences of individuals who have experienced being diagnosed with ASC following an initial diagnosis of and treatment for PD, this research may have important clinical implications for the care of individuals receiving care focussed on a diagnosis of PD who are later diagnosed with ASC.

A13. Please summarise your design and methodology. *It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.*

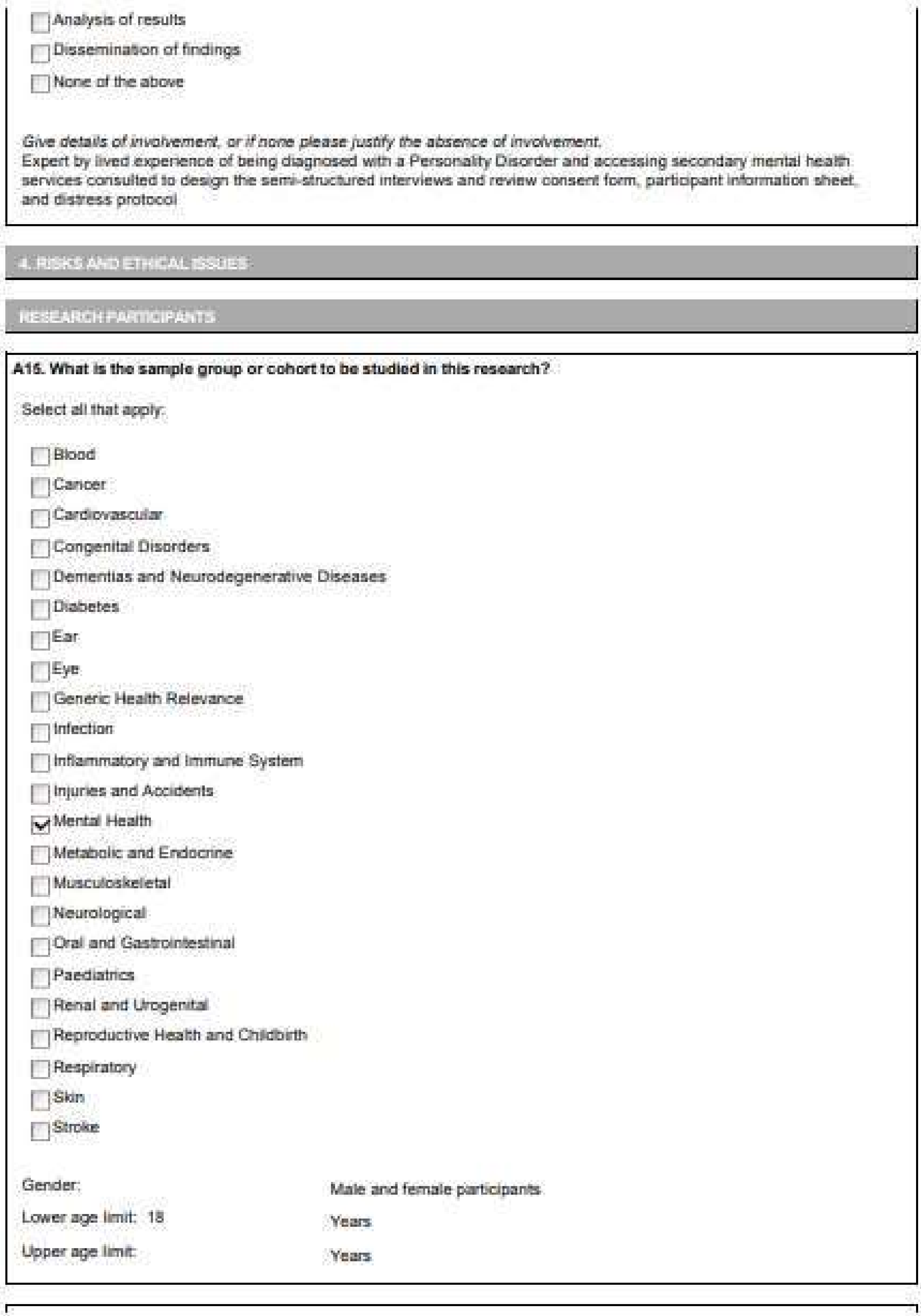
Design - The study will employ a qualitative design. Semi-structured interviews will be completed with participants, which will be auto recorded and transcribed by the Student Researcher.

Participants - Participants will be people who received an initial diagnosis of personality disorder from mental health services and were later diagnosed with autism spectrum condition. The study will recruit participants aged 18 and above. A minimum of 8 and a maximum of 12 participants will be recruited.

Method - The initial recruitment phase will recruit potential participants via social media. The study will be advertised through social media (Facebook, Twitter, Instagram, Threads) and the research advertisement will include the student researchers university email address and research telephone number. Potential participants will contact the student researcher to express their interest in participating, and will then be sent a screening questionnaire to assess whether they meet the inclusion criteria, which they will either complete and email back to the student researcher if they are able to, or will be completed with the student researcher over the phone.
All potential participants will be able to contact the Student Researcher for further information by telephone or email via the research poster and will be asked to complete a screening questionnaire, with their verbal consent, and responses will be considered in line with the study's inclusion and exclusion criteria. It will be explained to participants that as a result of their answers to the questionnaire they may be eligible for the interview part of the study.
If the initial recruitment phase does not successfully achieve the recruitment of between 8 and 12 participants, secondary mental health services in [redacted] will be approached to advertise the study via placing posters in their services and giving participant information sheets to service users who meet the inclusion criteria. Potential participants will be screened by the professionals responsible for their care (e.g. care co-ordinator) using the screening questionnaire with the participants verbal consent. Eligible NHS participants will be informed verbally by their care provider that they are eligible and will be able to contact the student researcher to express their interest in participating.
Responses to the screening questionnaire will be stored anonymously on a screening log given the sensitive nature of the information. If the responses to the demographic questionnaire satisfy these criteria, participants will be invited to arrange a suitable interview date, time, and format. Participants will also be sent the participant information sheet, consent form, and distress protocol at this time.
Interviews will begin with the Student Researcher going through the participant information sheet and distress protocol and obtaining informed consent via the consent form.
Participants will be asked to attend an interview session that will last approximately 1 hour, including time to go over the information sheet and consent form. Participants' confidentiality and right to withdraw will also be outlined.
Participants will be offered the opportunity to ask any further questions they may have about participating in the study before consent is obtained.
If participants become distressed during the interview opportunities will be given to take a break, discontinue the interview, or arrange to continue to interview at a later date.
Once the interview is complete participants will be debriefed and will have an opportunity to ask any further questions they may have about the study. Participants will also be directed to the support available outlined within the distress protocol at this time.
Analysis - Interviews conducted within this study will be recorded using an audio recorder and will be transcribed verbatim by the Student Researcher. Data will be anonymised using pseudonyms.

A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

☑ Design of the research
☐ Management of the research
☐ Undertaking the research



☐ Analysis of results
☐ Dissemination of findings
☐ None of the above

Give details of involvement, or if none please justify the absence of involvement.
Expert by lived experience of being diagnosed with a Personality Disorder and accessing secondary mental health services consulted to design the semi-structured interviews and review consent form, participant information sheet, and distress protocol

4. RISKS AND ETHICAL ISSUES

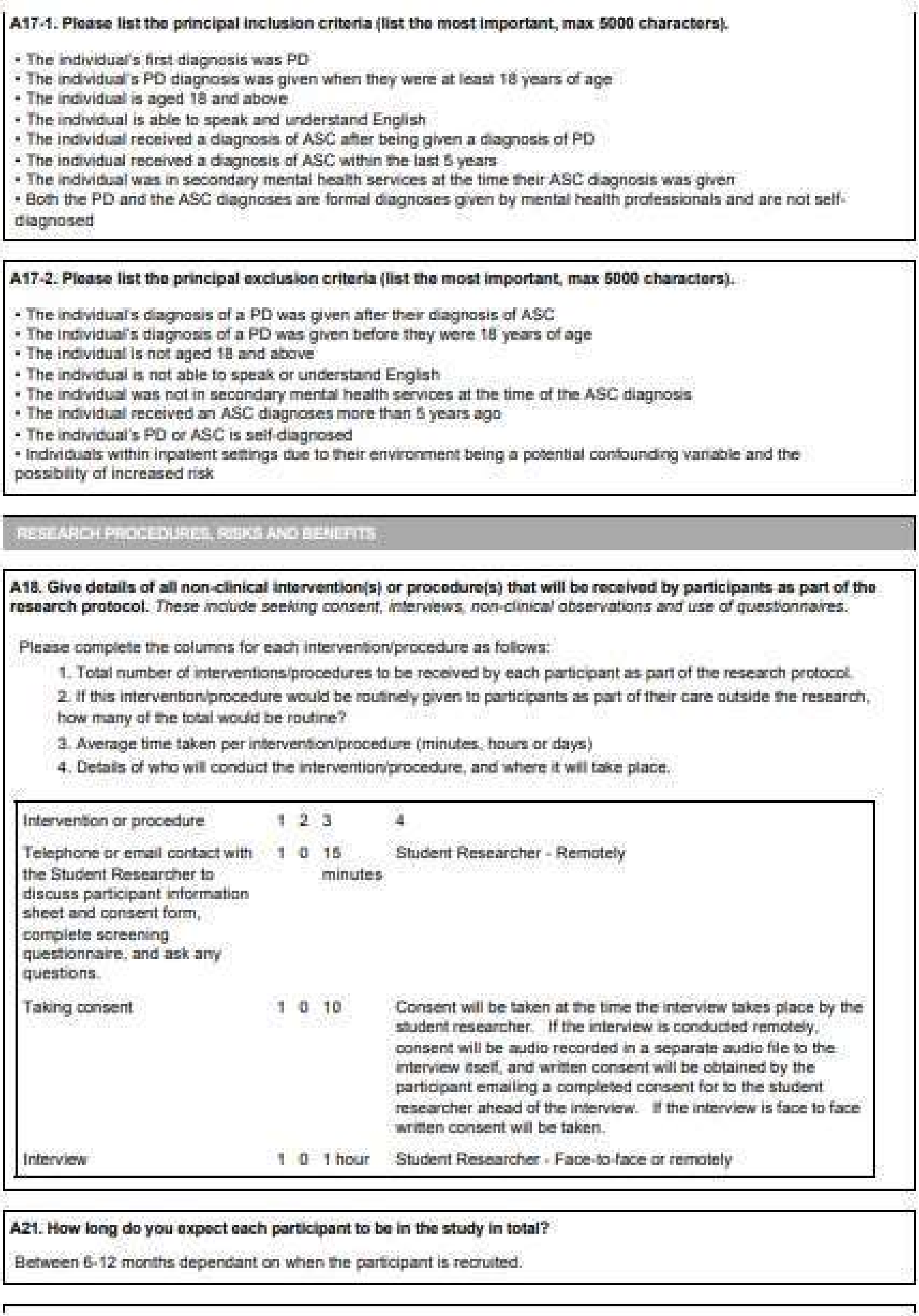
RESEARCH PARTICIPANTS

A15. What is the sample group or cohort to be studied in this research?

Select all that apply:

☐ Blood
☐ Cancer
☐ Cardiovascular
☐ Congenital Disorders
☐ Dementias and Neurodegenerative Diseases
☐ Diabetes
☐ Ear
☐ Eye
☐ Generic Health Relevance
☐ Infection
☐ Inflammatory and Immune System
☐ Injuries and Accidents
☑ Mental Health
☐ Metabolic and Endocrine
☐ Musculoskeletal
☐ Neurological
☐ Oral and Gastrointestinal
☐ Paediatrics
☐ Renal and Urogenital
☐ Reproductive Health and Childbirth
☐ Respiratory
☐ Skin
☐ Stroke

Gender:	Male and female participants
Lower age limit: 18	Years
Upper age limit:	Years



A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).

- The individual's first diagnosis was PD
- The individual's PD diagnosis was given when they were at least 18 years of age
- The individual is aged 18 and above
- The individual is able to speak and understand English
- The individual received a diagnosis of ASC after being given a diagnosis of PD
- The individual received a diagnosis of ASC within the last 5 years
- The individual was in secondary mental health services at the time their ASC diagnosis was given
- Both the PD and the ASC diagnoses are formal diagnoses given by mental health professionals and are not self-diagnosed

A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).

- The individual's diagnosis of a PD was given after their diagnosis of ASC
- The individual's diagnosis of a PD was given before they were 18 years of age
- The individual is not aged 18 and above
- The individual is not able to speak or understand English
- The individual was not in secondary mental health services at the time of the ASC diagnosis
- The individual received an ASC diagnoses more than 5 years ago
- The individual's PD or ASC is self-diagnosed
- Individuals within inpatient settings due to their environment being a potential confounding variable and the possibility of increased risk

RESEARCH PROCEDURES, RISKS AND BENEFITS

A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. *These include seeking consent, interviews, non-clinical observations and use of questionnaires.*

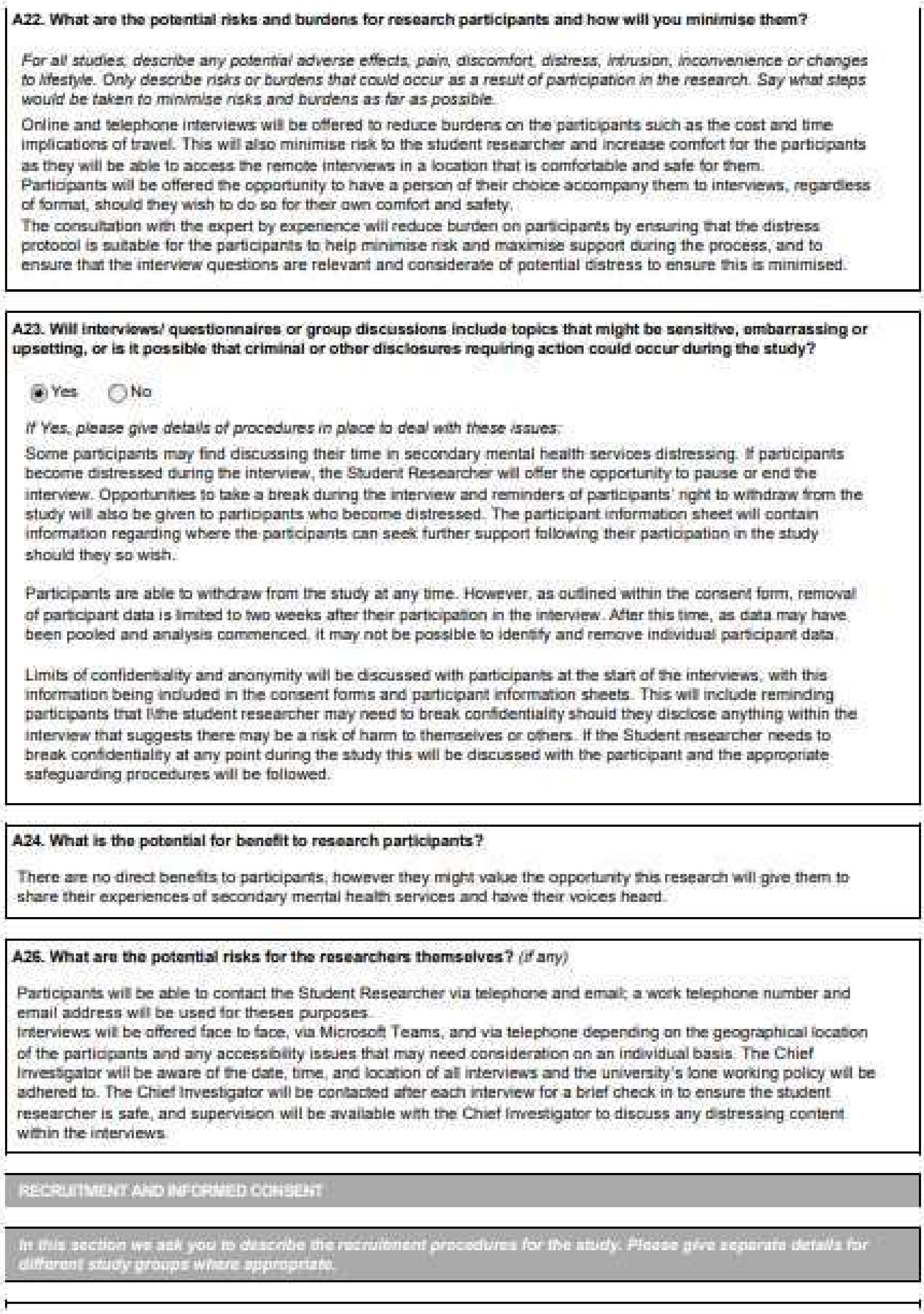
Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?
3. Average time taken per intervention/procedure (minutes, hours or days)
4. Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	1	2	3	4
Telephone or email contact with the Student Researcher to discuss participant information sheet and consent form, complete screening questionnaire, and ask any questions.	1	0	15 minutes	Student Researcher - Remotely
Taking consent	1	0	10	Consent will be taken at the time the interview takes place by the student researcher. If the interview is conducted remotely, consent will be audio recorded in a separate audio file to the interview itself, and written consent will be obtained by the participant emailing a completed consent for to the student researcher ahead of the interview. If the interview is face to face written consent will be taken.
Interview	1	0	1 hour	Student Researcher - Face-to-face or remotely

A21. How long do you expect each participant to be in the study in total?

Between 6-12 months dependant on when the participant is recruited.



A22. What are the potential risks and burdens for research participants and how will you minimise them?

For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.

Online and telephone interviews will be offered to reduce burdens on the participants such as the cost and time implications of travel. This will also minimise risk to the student researcher and increase comfort for the participants as they will be able to access the remote interviews in a location that is comfortable and safe for them.
Participants will be offered the opportunity to have a person of their choice accompany them to interviews, regardless of format, should they wish to do so for their own comfort and safety.
The consultation with the expert by experience will reduce burden on participants by ensuring that the distress protocol is suitable for the participants to help minimise risk and maximise support during the process, and to ensure that the interview questions are relevant and considerate of potential distress to ensure this is minimised.

A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?

● Yes ○ No

If Yes, please give details of procedures in place to deal with these issues:

Some participants may find discussing their time in secondary mental health services distressing. If participants become distressed during the interview, the Student Researcher will offer the opportunity to pause or end the interview. Opportunities to take a break during the interview and reminders of participants' right to withdraw from the study will also be given to participants who become distressed. The participant information sheet will contain information regarding where the participants can seek further support following their participation in the study should they so wish.

Participants are able to withdraw from the study at any time. However, as outlined within the consent form, removal of participant data is limited to two weeks after their participation in the interview. After this time, as data may have been pooled and analysis commenced, it may not be possible to identify and remove individual participant data.

Limits of confidentiality and anonymity will be discussed with participants at the start of the interviews, with this information being included in the consent forms and participant information sheets. This will include reminding participants that I/the student researcher may need to break confidentiality should they disclose anything within the interview that suggests there may be a risk of harm to themselves or others. If the Student researcher needs to break confidentiality at any point during the study this will be discussed with the participant and the appropriate safeguarding procedures will be followed.

A24. What is the potential for benefit to research participants?

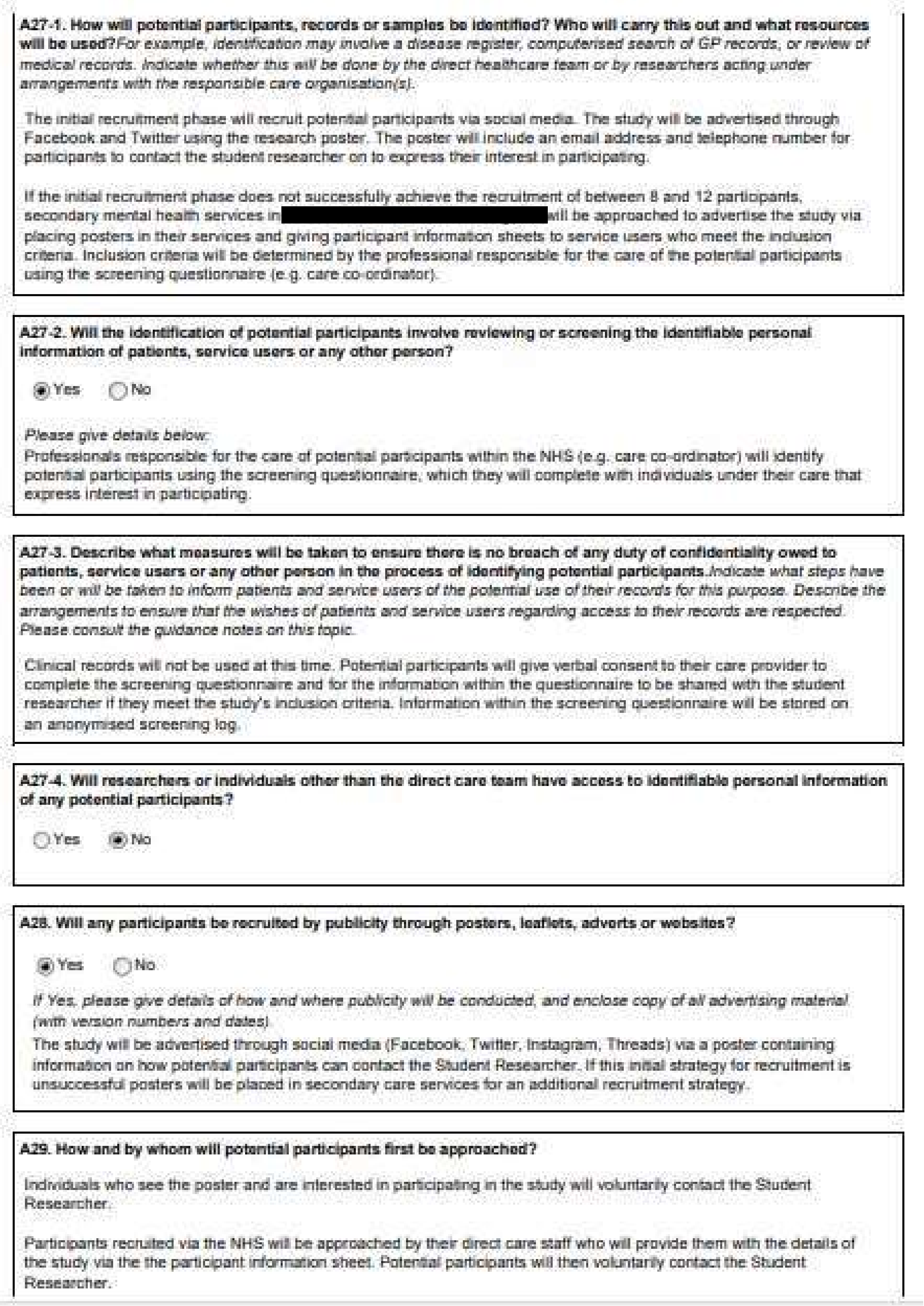
There are no direct benefits to participants, however they might value the opportunity this research will give them to share their experiences of secondary mental health services and have their voices heard.

A26. What are the potential risks for the researchers themselves? *(if any)*

Participants will be able to contact the Student Researcher via telephone and email; a work telephone number and email address will be used for theses purposes.
Interviews will be offered face to face, via Microsoft Teams, and via telephone depending on the geographical location of the participants and any accessibility issues that may need consideration on an individual basis. The Chief Investigator will be aware of the date, time, and location of all interviews and the university's lone working policy will be adhered to. The Chief Investigator will be contacted after each interview for a brief check in to ensure the student researcher is safe, and supervision will be available with the Chief Investigator to discuss any distressing content within the interviews.

RECRUITMENT AND INFORMED CONSENT

In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.



A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used? *For example, identification may involve a disease register, computerised search of GP records, or review of medical records. Indicate whether this will be done by the direct healthcare team or by researchers acting under arrangements with the responsible care organisation(s).*

The initial recruitment phase will recruit potential participants via social media. The study will be advertised through Facebook and Twitter using the research poster. The poster will include an email address and telephone number for participants to contact the student researcher on to express their interest in participating.

If the initial recruitment phase does not successfully achieve the recruitment of between 8 and 12 participants, secondary mental health services in [redacted] will be approached to advertise the study via placing posters in their services and giving participant information sheets to service users who meet the inclusion criteria. Inclusion criteria will be determined by the professional responsible for the care of the potential participants using the screening questionnaire (e.g. care co-ordinator).

A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?

● Yes ○ No

Please give details below:
Professionals responsible for the care of potential participants within the NHS (e.g. care co-ordinator) will identify potential participants using the screening questionnaire, which they will complete with individuals under their care that express interest in participating.

A27-3. Describe what measures will be taken to ensure there is no breach of any duty of confidentiality owed to patients, service users or any other person in the process of identifying potential participants. *Indicate what steps have been or will be taken to inform patients and service users of the potential use of their records for this purpose. Describe the arrangements to ensure that the wishes of patients and service users regarding access to their records are respected. Please consult the guidance notes on this topic.*

Clinical records will not be used at this time. Potential participants will give verbal consent to their care provider to complete the screening questionnaire and for the information within the questionnaire to be shared with the student researcher if they meet the study's inclusion criteria. Information within the screening questionnaire will be stored on an anonymised screening log.

A27-4. Will researchers or individuals other than the direct care team have access to identifiable personal information of any potential participants?

○ Yes ● No

A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?

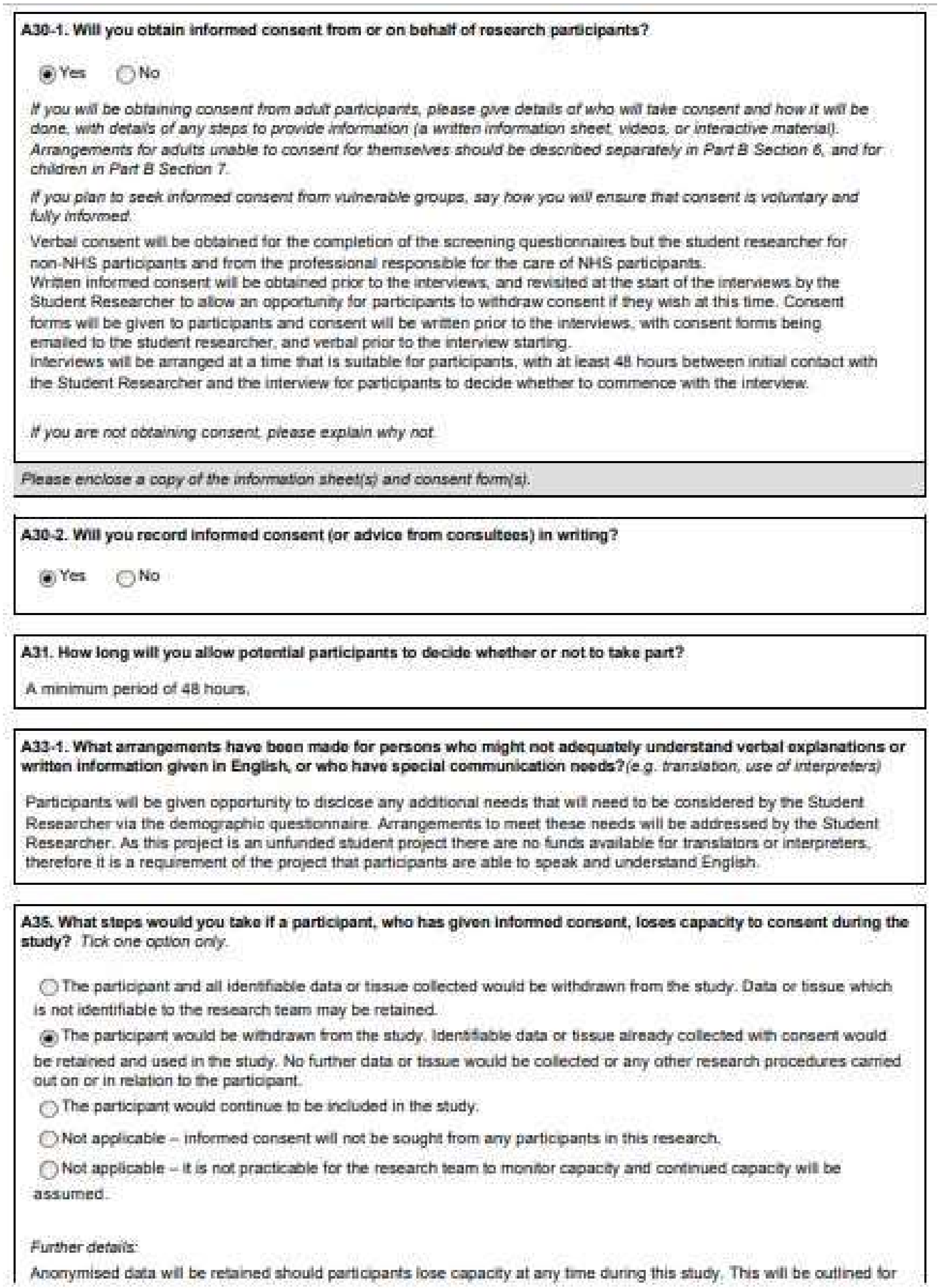
● Yes ○ No

If Yes, please give details of how and where publicity will be conducted, and enclose copy of all advertising material (with version numbers and dates).
The study will be advertised through social media (Facebook, Twitter, Instagram, Threads) via a poster containing information on how potential participants can contact the Student Researcher. If this initial strategy for recruitment is unsuccessful posters will be placed in secondary care services for an additional recruitment strategy.

A29. How and by whom will potential participants first be approached?

Individuals who see the poster and are interested in participating in the study will voluntarily contact the Student Researcher.

Participants recruited via the NHS will be approached by their direct care staff who will provide them with the details of the study via the the participant information sheet. Potential participants will then voluntarily contact the Student Researcher.



A30-1. Will you obtain informed consent from or on behalf of research participants?

● Yes ○ No

If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.

If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.

Verbal consent will be obtained for the completion of the screening questionnaires but the student researcher for non-NHS participants and from the professional responsible for the care of NHS participants.
Written informed consent will be obtained prior to the interviews, and revisited at the start of the interviews by the Student Researcher to allow an opportunity for participants to withdraw consent if they wish at this time. Consent forms will be given to participants and consent will be written prior to the interviews, with consent forms being emailed to the student researcher, and verbal prior to the interview starting.
Interviews will be arranged at a time that is suitable for participants, with at least 48 hours between initial contact with the Student Researcher and the interview for participants to decide whether to commence with the interview.

If you are not obtaining consent, please explain why not.

Please enclose a copy of the information sheet(s) and consent form(s).

A30-2. Will you record informed consent (or advice from consultees) in writing?

● Yes ○ No

A31. How long will you allow potential participants to decide whether or not to take part?

A minimum period of 48 hours.

A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs?*(e.g. translation, use of interpreters)*

Participants will be given opportunity to disclose any additional needs that will need to be considered by the Student Researcher via the demographic questionnaire. Arrangements to meet these needs will be addressed by the Student Researcher. As this project is an unfunded student project there are no funds available for translators or interpreters, therefore it is a requirement of the project that participants are able to speak and understand English.

A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? *Tick one option only.*

○ The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.

● The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.

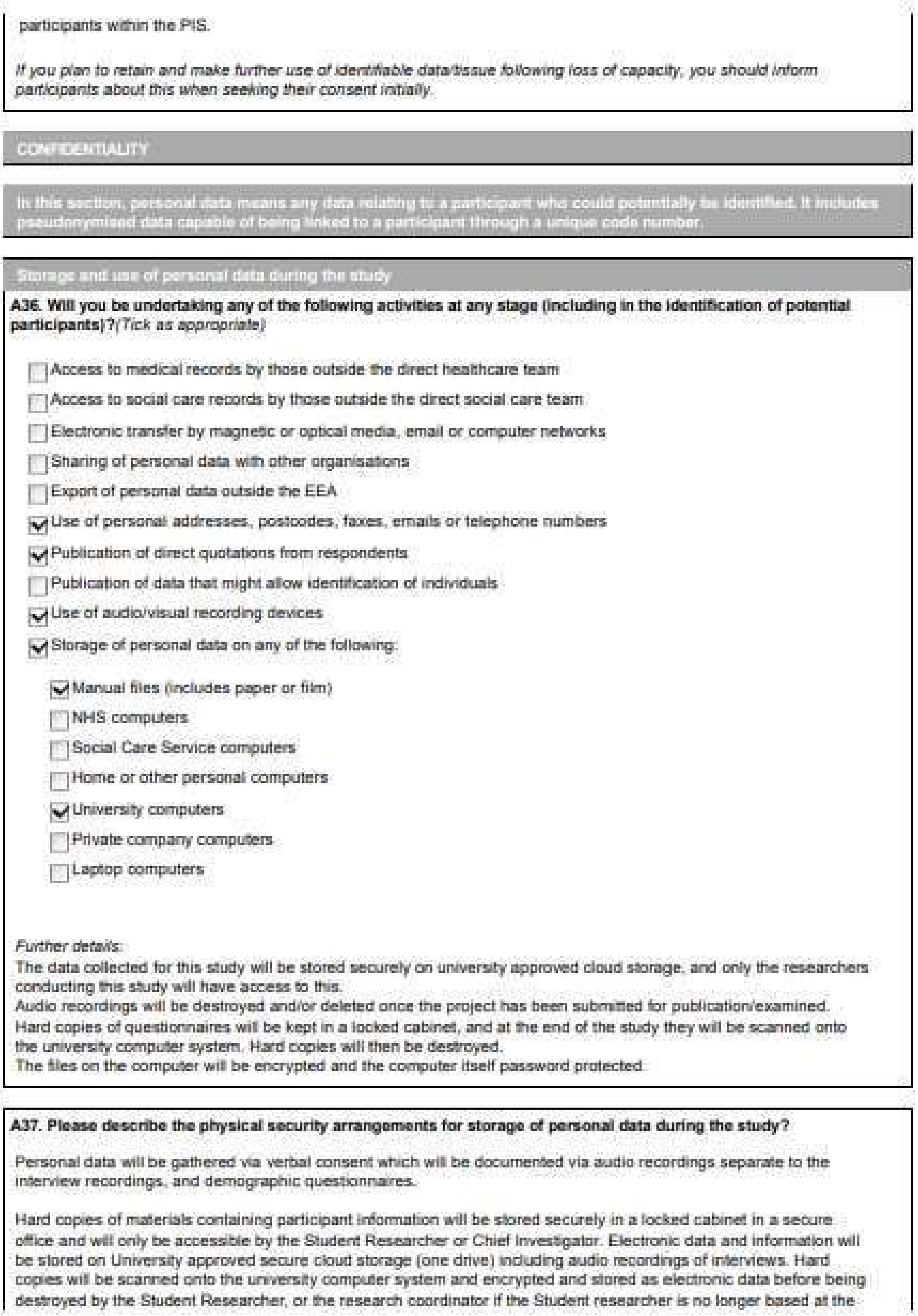
○ The participant would continue to be included in the study.

○ Not applicable – informed consent will not be sought from any participants in this research.

○ Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

Further details:

Anonymised data will be retained should participants lose capacity at any time during this study. This will be outlined for



participants within the PIS.

If you plan to retain and make further use of identifiable data/tissue following loss of capacity, you should inform participants about this when seeking their consent initially.

CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

Storage and use of personal data during the study

A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)?*(Tick as appropriate)*

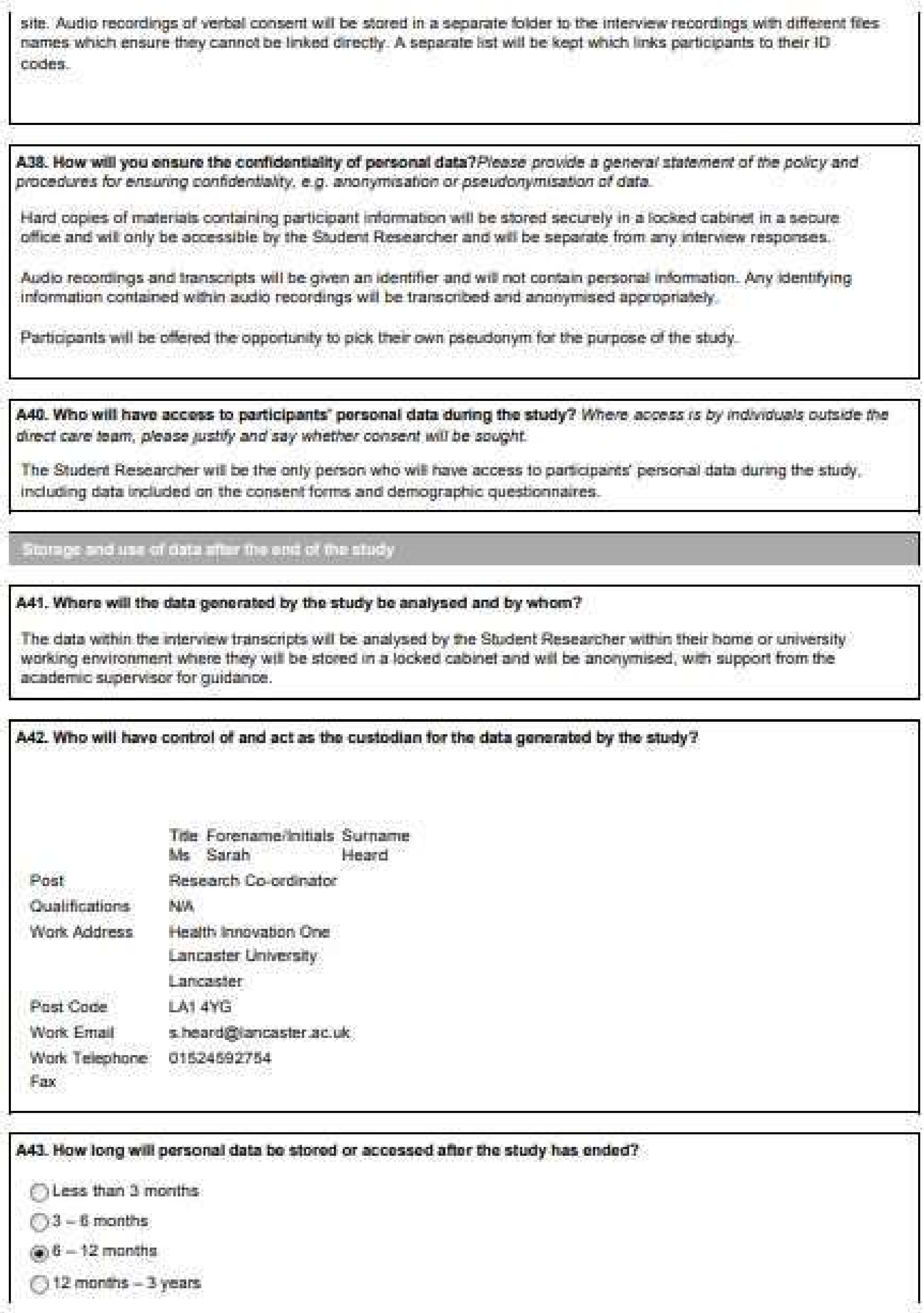
- ☐ Access to medical records by those outside the direct healthcare team
- ☐ Access to social care records by those outside the direct social care team
- ☐ Electronic transfer by magnetic or optical media, email or computer networks
- ☐ Sharing of personal data with other organisations
- ☐ Export of personal data outside the EEA
- ☑ Use of personal addresses, postcodes, faxes, emails or telephone numbers
- ☑ Publication of direct quotations from respondents
- ☐ Publication of data that might allow identification of individuals
- ☑ Use of audio/visual recording devices
- ☑ Storage of personal data on any of the following:
  - ☑ Manual files (includes paper or film)
  - ☐ NHS computers
  - ☐ Social Care Service computers
  - ☐ Home or other personal computers
  - ☑ University computers
  - ☐ Private company computers
  - ☐ Laptop computers

Further details:
The data collected for this study will be stored securely on university approved cloud storage, and only the researchers conducting this study will have access to this.
Audio recordings will be destroyed and/or deleted once the project has been submitted for publication/examined.
Hard copies of questionnaires will be kept in a locked cabinet, and at the end of the study they will be scanned onto the university computer system. Hard copies will then be destroyed.
The files on the computer will be encrypted and the computer itself password protected.

A37. Please describe the physical security arrangements for storage of personal data during the study?

Personal data will be gathered via verbal consent which will be documented via audio recordings separate to the interview recordings, and demographic questionnaires.

Hard copies of materials containing participant information will be stored securely in a locked cabinet in a secure office and will only be accessible by the Student Researcher or Chief Investigator. Electronic data and information will be stored on University approved secure cloud storage (one drive) including audio recordings of interviews. Hard copies will be scanned onto the university computer system and encrypted and stored as electronic data before being destroyed by the Student Researcher, or the research coordinator if the Student researcher is no longer based at the



site. Audio recordings of verbal consent will be stored in a separate folder to the interview recordings with different files names which ensure they cannot be linked directly. A separate list will be kept which links participants to their ID codes.

A38. How will you ensure the confidentiality of personal data?*Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.*

Hard copies of materials containing participant information will be stored securely in a locked cabinet in a secure office and will only be accessible by the Student Researcher and will be separate from any interview responses.

Audio recordings and transcripts will be given an identifier and will not contain personal information. Any identifying information contained within audio recordings will be transcribed and anonymised appropriately.

Participants will be offered the opportunity to pick their own pseudonym for the purpose of the study.

A40. Who will have access to participants' personal data during the study? *Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.*

The Student Researcher will be the only person who will have access to participants' personal data during the study, including data included on the consent forms and demographic questionnaires.

Storage and use of data after the end of the study

A41. Where will the data generated by the study be analysed and by whom?

The data within the interview transcripts will be analysed by the Student Researcher within their home or university working environment where they will be stored in a locked cabinet and will be anonymised, with support from the academic supervisor for guidance.

A42. Who will have control of and act as the custodian for the data generated by the study?

	Title	Forename/Initials	Surname
	Ms	Sarah	Heard
Post	Research Co-ordinator		
Qualifications	N/A		
Work Address	Health Innovation One Lancaster University Lancaster		
Post Code	LA1 4YG		
Work Email	s.heard@lancaster.ac.uk		
Work Telephone	01524592754		
Fax			

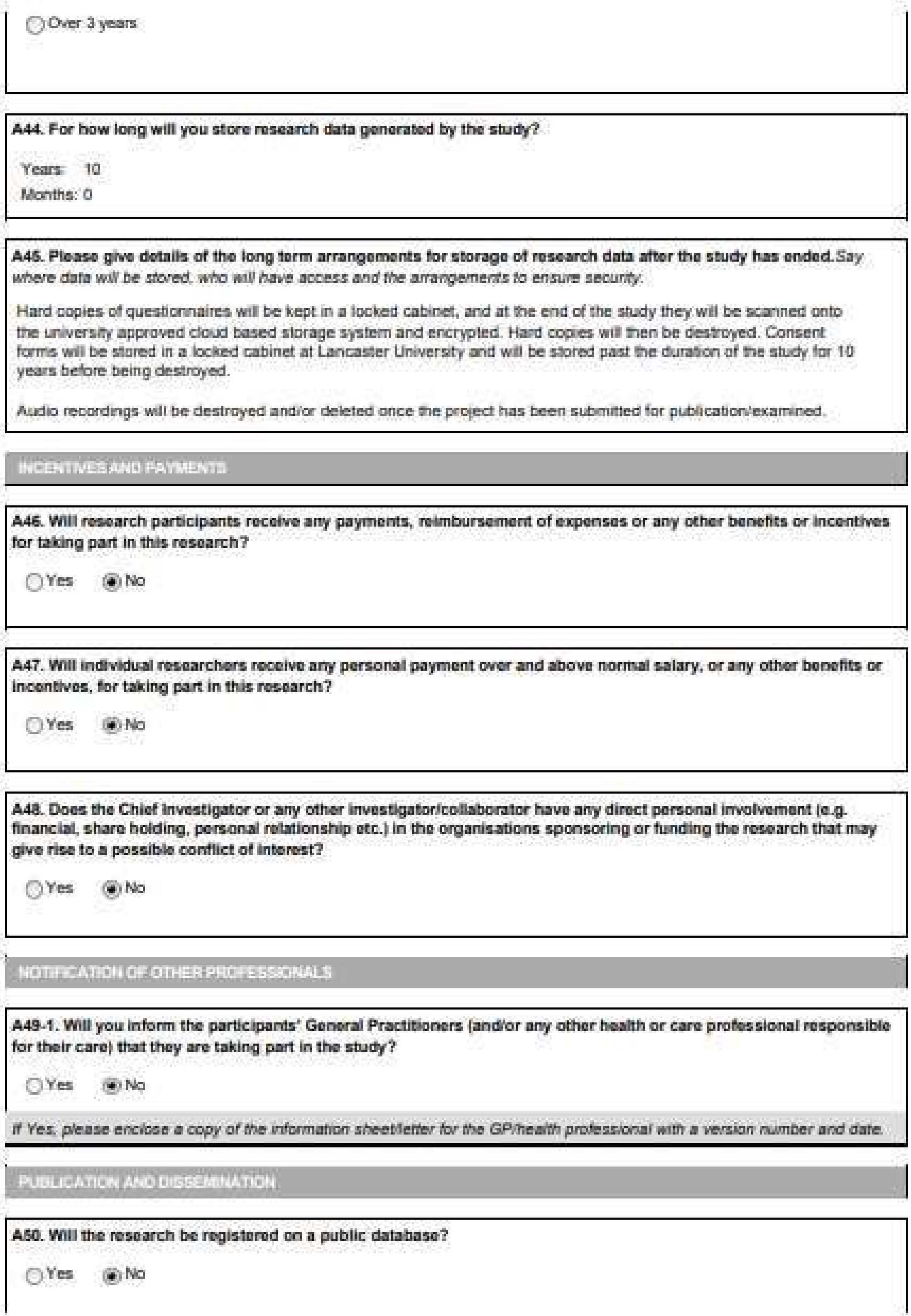
A43. How long will personal data be stored or accessed after the study has ended?

○ Less than 3 months

○ 3 – 6 months

● 6 – 12 months

○ 12 months – 3 years



○ Over 3 years

A44. For how long will you store research data generated by the study?

Years: 10
Months: 0

A45. Please give details of the long term arrangements for storage of research data after the study has ended. *Say where data will be stored, who will have access and the arrangements to ensure security.*

Hard copies of questionnaires will be kept in a locked cabinet, and at the end of the study they will be scanned onto the university approved cloud based storage system and encrypted. Hard copies will then be destroyed. Consent forms will be stored in a locked cabinet at Lancaster University and will be stored past the duration of the study for 10 years before being destroyed.

Audio recordings will be destroyed and/or deleted once the project has been submitted for publication/examined.

INCENTIVES AND PAYMENTS

A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?

○ Yes ● No

A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?

○ Yes ● No

A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?

○ Yes ● No

NOTIFICATION OF OTHER PROFESSIONALS

A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?

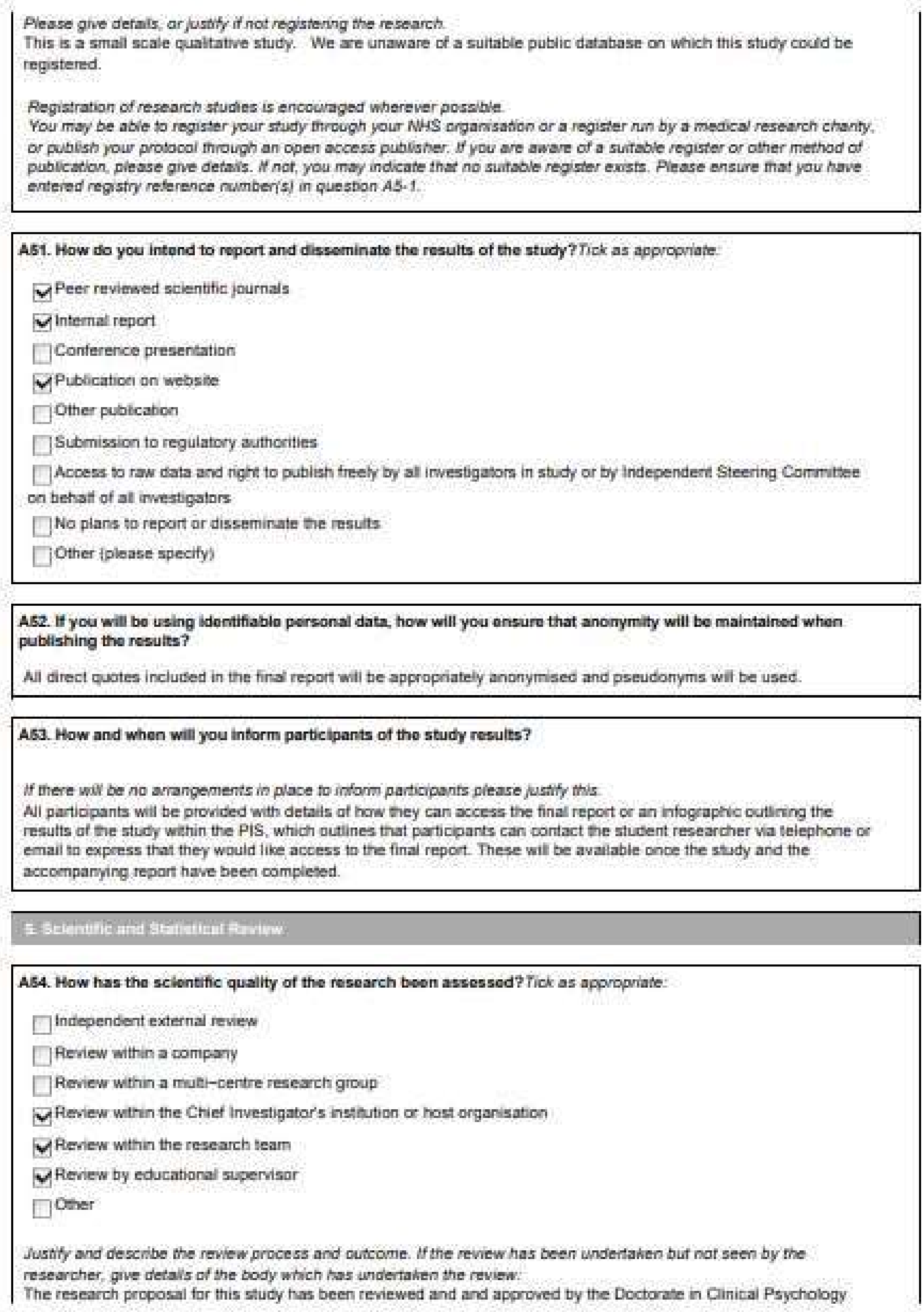
○ Yes ● No

If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.

PUBLICATION AND DISSEMINATION

A50. Will the research be registered on a public database?

○ Yes ● No



Please give details, or justify if not registering the research.
This is a small scale qualitative study. We are unaware of a suitable public database on which this study could be registered.

Registration of research studies is encouraged wherever possible.
You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you are aware of a suitable register or other method of publication, please give details. If not, you may indicate that no suitable register exists. Please ensure that you have entered registry reference number(s) in question A5-1.

A51. How do you intend to report and disseminate the results of the study? *Tick as appropriate:*

☑ Peer reviewed scientific journals
☑ Internal report
☐ Conference presentation
☑ Publication on website
☐ Other publication
☐ Submission to regulatory authorities
☐ Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators
☐ No plans to report or disseminate the results
☐ Other (please specify)

A52. If you will be using identifiable personal data, how will you ensure that anonymity will be maintained when publishing the results?

All direct quotes included in the final report will be appropriately anonymised and pseudonyms will be used.

A53. How and when will you inform participants of the study results?

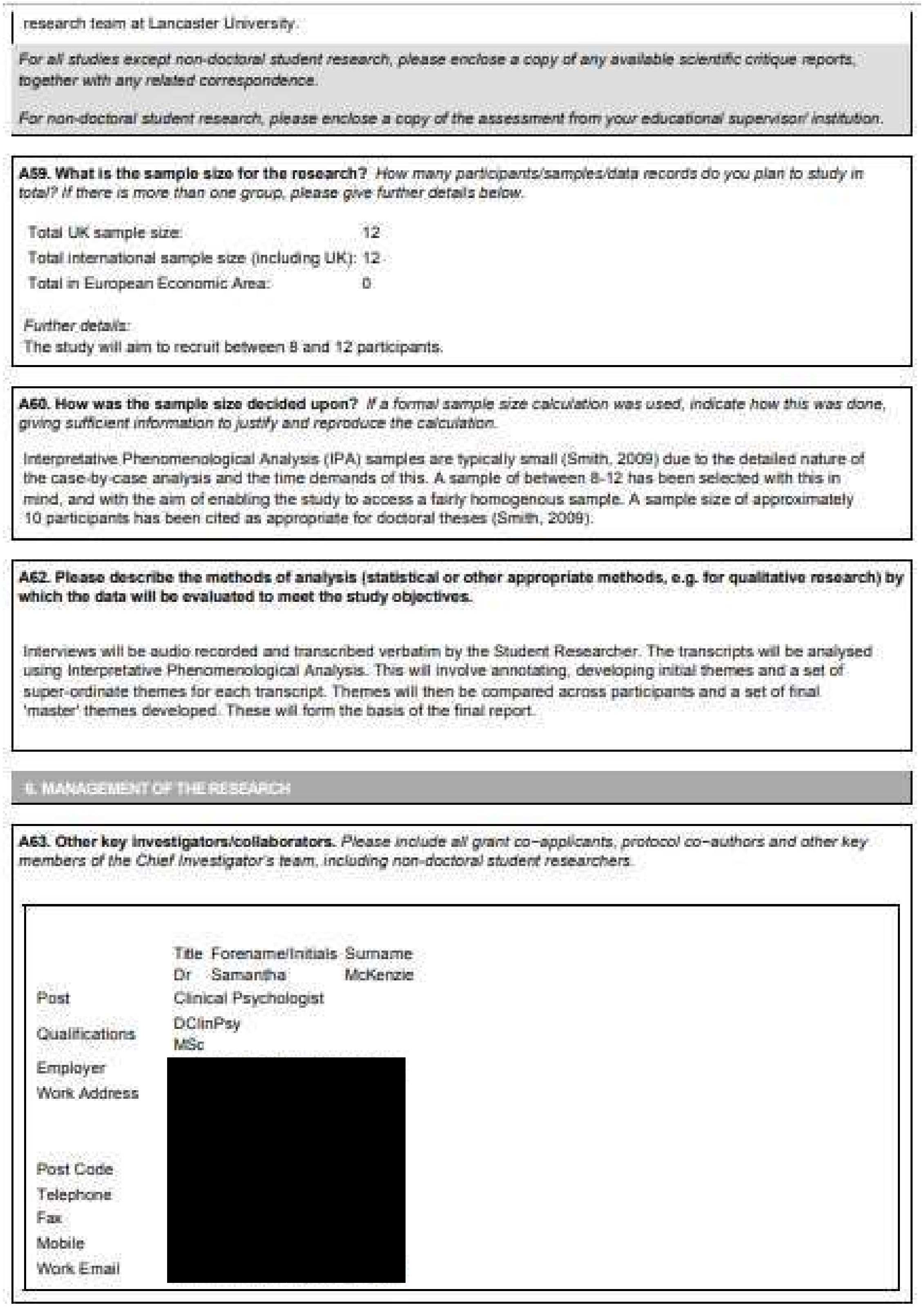
If there will be no arrangements in place to inform participants please justify this.
All participants will be provided with details of how they can access the final report or an infographic outlining the results of the study within the PIS, which outlines that participants can contact the student researcher via telephone or email to express that they would like access to the final report. These will be available once the study and the accompanying report have been completed.

5. Scientific and Statistical Review

A54. How has the scientific quality of the research been assessed? *Tick as appropriate:*

☐ Independent external review
☐ Review within a company
☐ Review within a multi-centre research group
☑ Review within the Chief Investigator's institution or host organisation
☑ Review within the research team
☑ Review by educational supervisor
☐ Other

Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:
The research proposal for this study has been reviewed and and approved by the Doctorate in Clinical Psychology



research team at Lancaster University.

For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.

For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.

A59. What is the sample size for the research? *How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.*

Total UK sample size:	12
Total international sample size (including UK):	12
Total in European Economic Area:	0

Further details:
The study will aim to recruit between 8 and 12 participants.

A60. How was the sample size decided upon? *If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.*

Interpretative Phenomenological Analysis (IPA) samples are typically small (Smith, 2009) due to the detailed nature of the case-by-case analysis and the time demands of this. A sample of between 8-12 has been selected with this in mind, and with the aim of enabling the study to access a fairly homogenous sample. A sample size of approximately 10 participants has been cited as appropriate for doctoral theses (Smith, 2009).

A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.

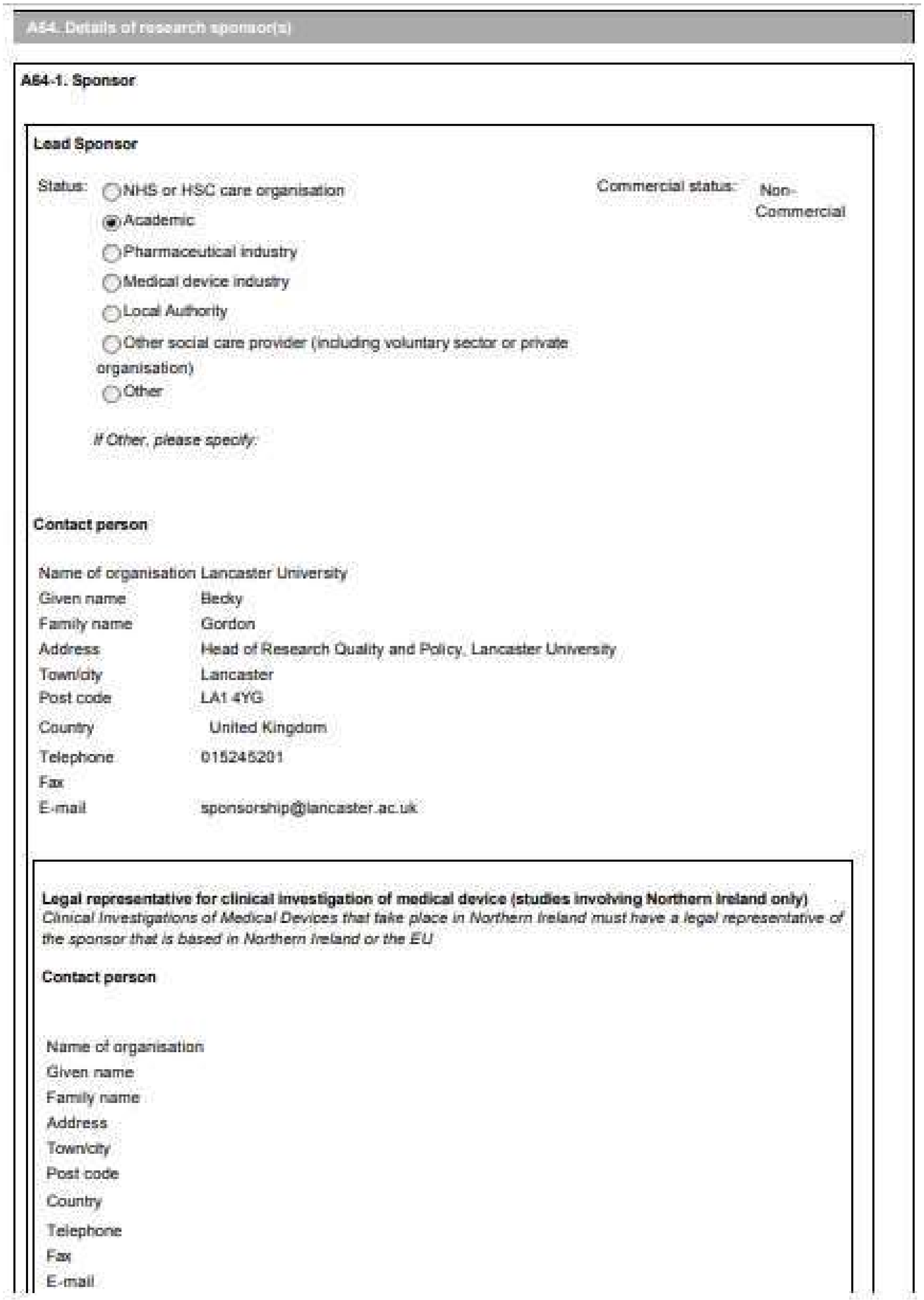
Interviews will be audio recorded and transcribed verbatim by the Student Researcher. The transcripts will be analysed using Interpretative Phenomenological Analysis. This will involve annotating, developing initial themes and a set of super-ordinate themes for each transcript. Themes will then be compared across participants and a set of final 'master' themes developed. These will form the basis of the final report.

6. MANAGEMENT OF THE RESEARCH

A63. Other key investigators/collaborators. *Please include all grant co-applicants, protocol co-authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.*

	Title	Forename/Initials	Surname
	Dr	Samantha	McKenzie

Post: Clinical Psychologist
Qualifications: DClinPsy
MSc
Employer [redacted]
Work Address
Post Code
Telephone
Fax
Mobile
Work Email



A64. Details of research sponsor(s)

A64-1. Sponsor

Lead Sponsor

Status:
○ NHS or HSC care organisation
● Academic
○ Pharmaceutical industry
○ Medical device industry
○ Local Authority
○ Other social care provider (including voluntary sector or private organisation)
○ Other

If Other, please specify:

Commercial status: Non-Commercial

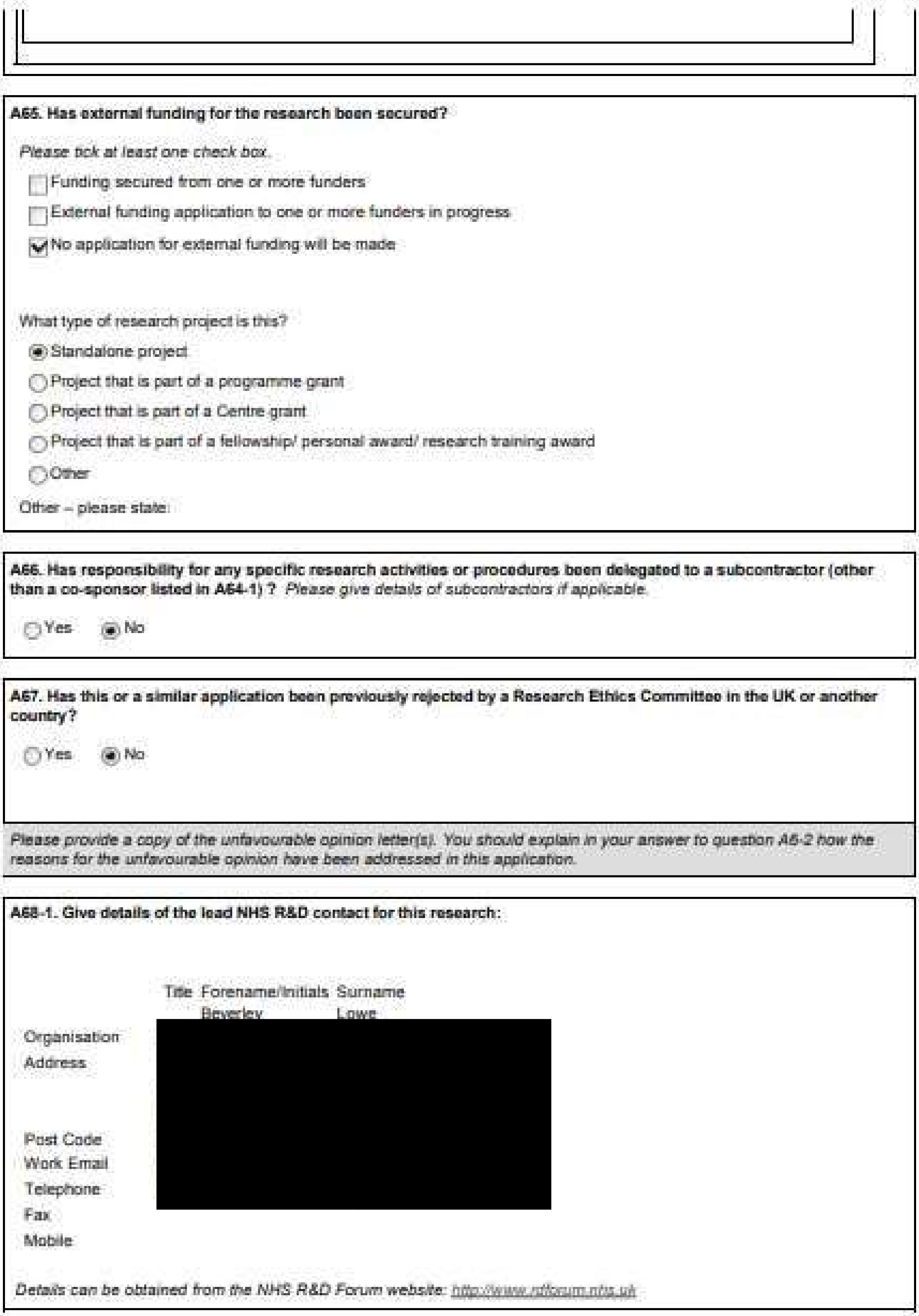
Contact person

Name of organisation	Lancaster University
Given name	Becky
Family name	Gordon
Address	Head of Research Quality and Policy, Lancaster University
Town/city	Lancaster
Post code	LA1 4YG
Country	United Kingdom
Telephone	015246201
Fax	
E-mail	sponsorship@lancaster.ac.uk

Legal representative for clinical investigation of medical device (studies involving Northern Ireland only)
Clinical Investigations of Medical Devices that take place in Northern Ireland must have a legal representative of the sponsor that is based in Northern Ireland or the EU

Contact person

Name of organisation	
Given name	
Family name	
Address	
Town/city	
Post code	
Country	
Telephone	
Fax	
E-mail	



A65. Has external funding for the research been secured?

Please tick at least one check box.

☐ Funding secured from one or more funders
☐ External funding application to one or more funders in progress
☑ No application for external funding will be made

What type of research project is this?

● Standalone project
○ Project that is part of a programme grant
○ Project that is part of a Centre grant
○ Project that is part of a fellowship/ personal award/ research training award
○ Other

Other – please state:

A66. Has responsibility for any specific research activities or procedures been delegated to a subcontractor (other than a co-sponsor listed in A64-1) ? *Please give details of subcontractors if applicable.*

○ Yes ● No

A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?

○ Yes ● No

Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.

A68-1. Give details of the lead NHS R&D contact for this research:

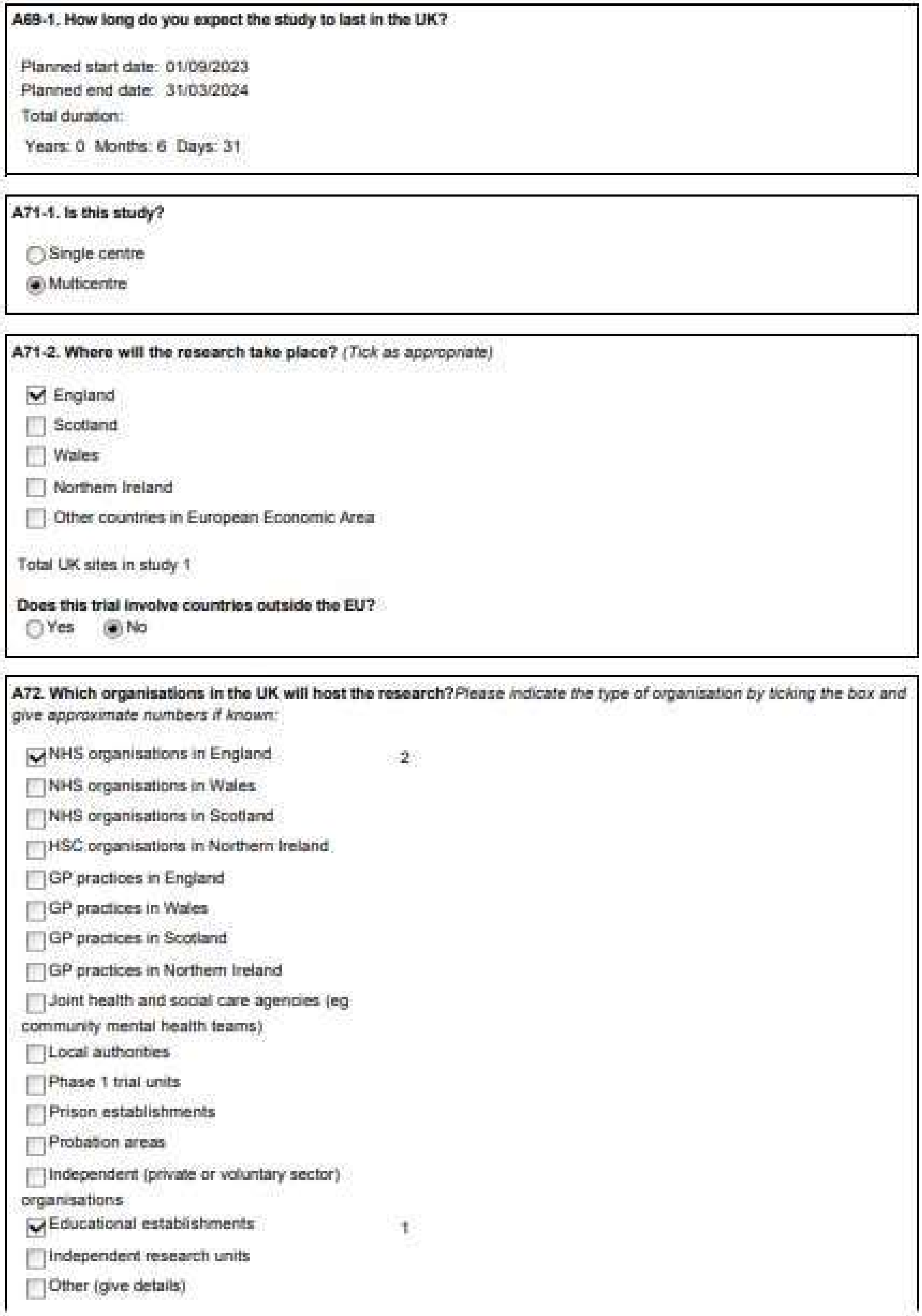
Title Forename/Initials Surname

[redacted]

Organisation
Address

Post Code
Work Email
Telephone
Fax
Mobile

Details can be obtained from the NHS R&D Forum website: http://www.rdforum.nhs.uk



A69-1. How long do you expect the study to last in the UK?

Planned start date: 01/09/2023
Planned end date: 31/03/2024
Total duration:
Years: 0 Months: 6 Days: 31

A71-1. Is this study?

○ Single centre
● Multicentre

A71-2. Where will the research take place? *(Tick as appropriate)*

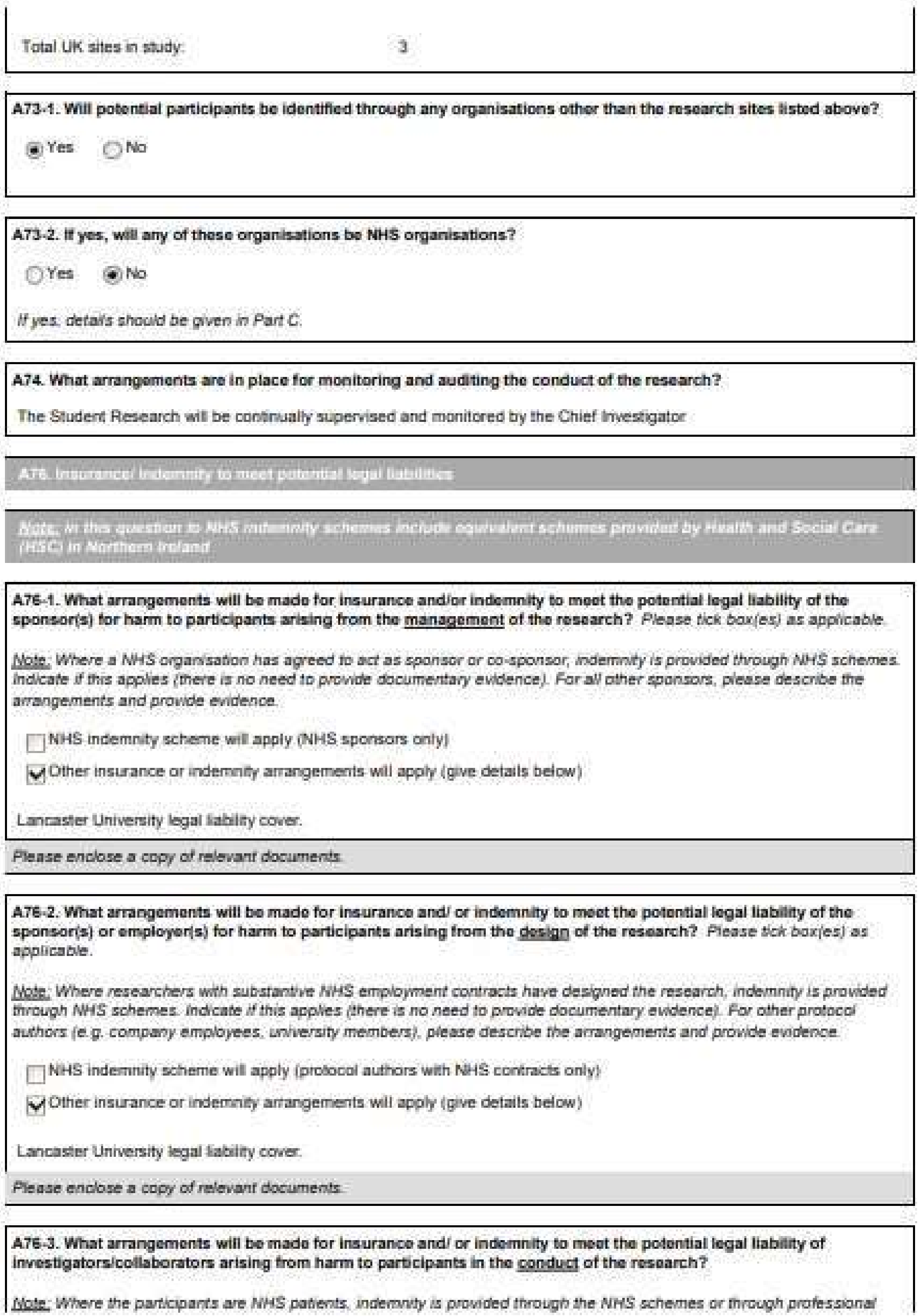
☑ England
☐ Scotland
☐ Wales
☐ Northern Ireland
☐ Other countries in European Economic Area

Total UK sites in study 1

Does this trial involve countries outside the EU?
○ Yes ● No

A72. Which organisations in the UK will host the research? *Please indicate the type of organisation by ticking the box and give approximate numbers if known:*

☑ NHS organisations in England	2
☐ NHS organisations in Wales	
☐ NHS organisations in Scotland	
☐ HSC organisations in Northern Ireland	
☐ GP practices in England	
☐ GP practices in Wales	
☐ GP practices in Scotland	
☐ GP practices in Northern Ireland	
☐ Joint health and social care agencies (eg community mental health teams)	
☐ Local authorities	
☐ Phase 1 trial units	
☐ Prison establishments	
☐ Probation areas	
☐ Independent (private or voluntary sector) organisations	
☑ Educational establishments	1
☐ Independent research units	
☐ Other (give details)	



Total UK sites in study: 3

A73-1. Will potential participants be identified through any organisations other than the research sites listed above?

● Yes ○ No

A73-2. If yes, will any of these organisations be NHS organisations?

○ Yes ● No

If yes, details should be given in Part C.

A74. What arrangements are in place for monitoring and auditing the conduct of the research?

The Student Research will be continually supervised and monitored by the Chief Investigator

A76. Insurance/ indemnity to meet potential legal liabilities

***Note:** in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland*

A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research? *Please tick box(es) as applicable.*

Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.

☐ NHS indemnity scheme will apply (NHS sponsors only)

☑ Other insurance or indemnity arrangements will apply (give details below)

Lancaster University legal liability cover.

Please enclose a copy of relevant documents.

A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research? *Please tick box(es) as applicable.*

Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.

☐ NHS indemnity scheme will apply (protocol authors with NHS contracts only)

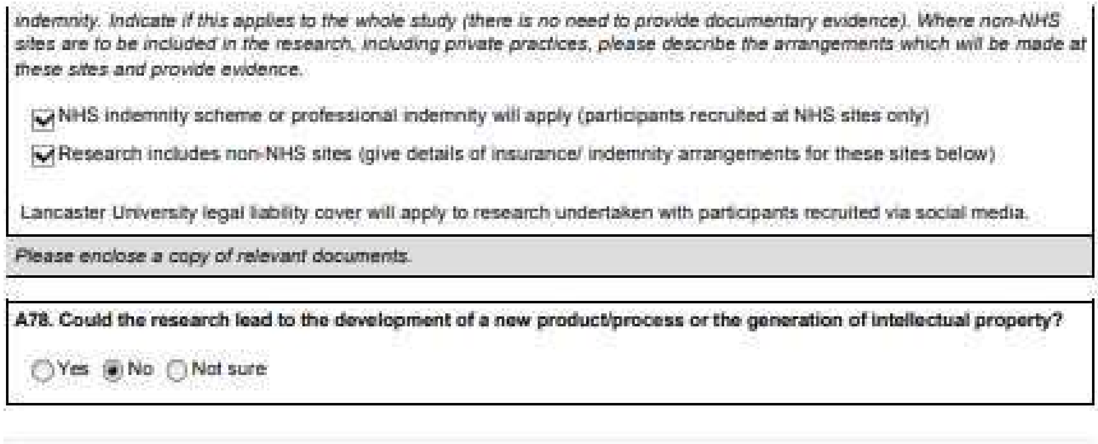
☑ Other insurance or indemnity arrangements will apply (give details below)

Lancaster University legal liability cover.

Please enclose a copy of relevant documents.

A76-3. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the conduct of the research?

Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional



indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.

☑ NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)

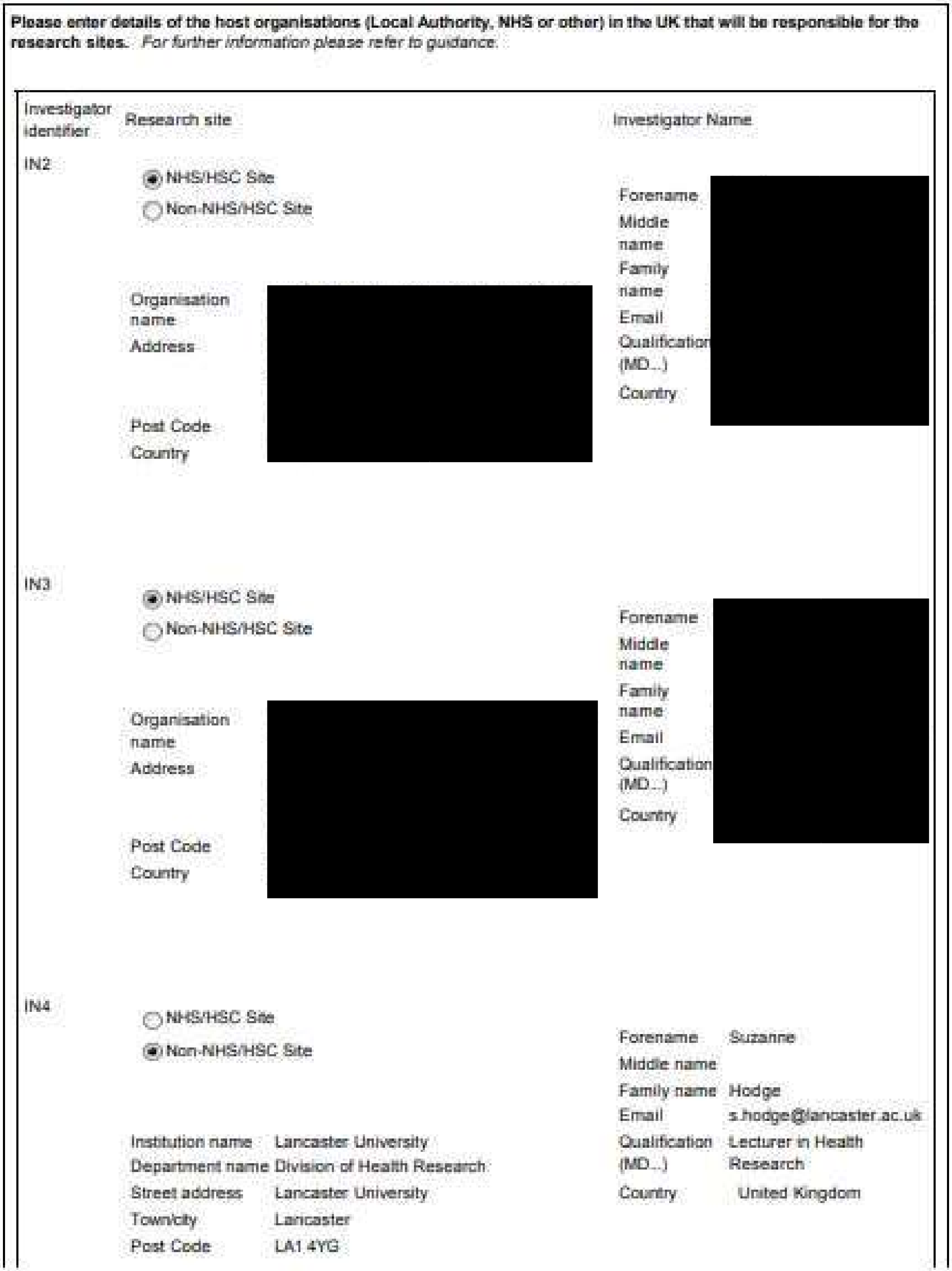
☑ Research includes non-NHS sites (give details of insurance/ indemnity arrangements for these sites below)

Lancaster University legal liability cover will apply to research undertaken with participants recruited via social media.

Please enclose a copy of relevant documents.

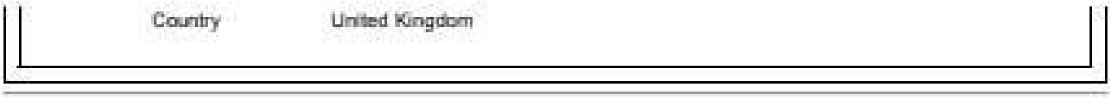
A78. Could the research lead to the development of a new product/process or the generation of intellectual property?

○ Yes ● No ○ Not sure

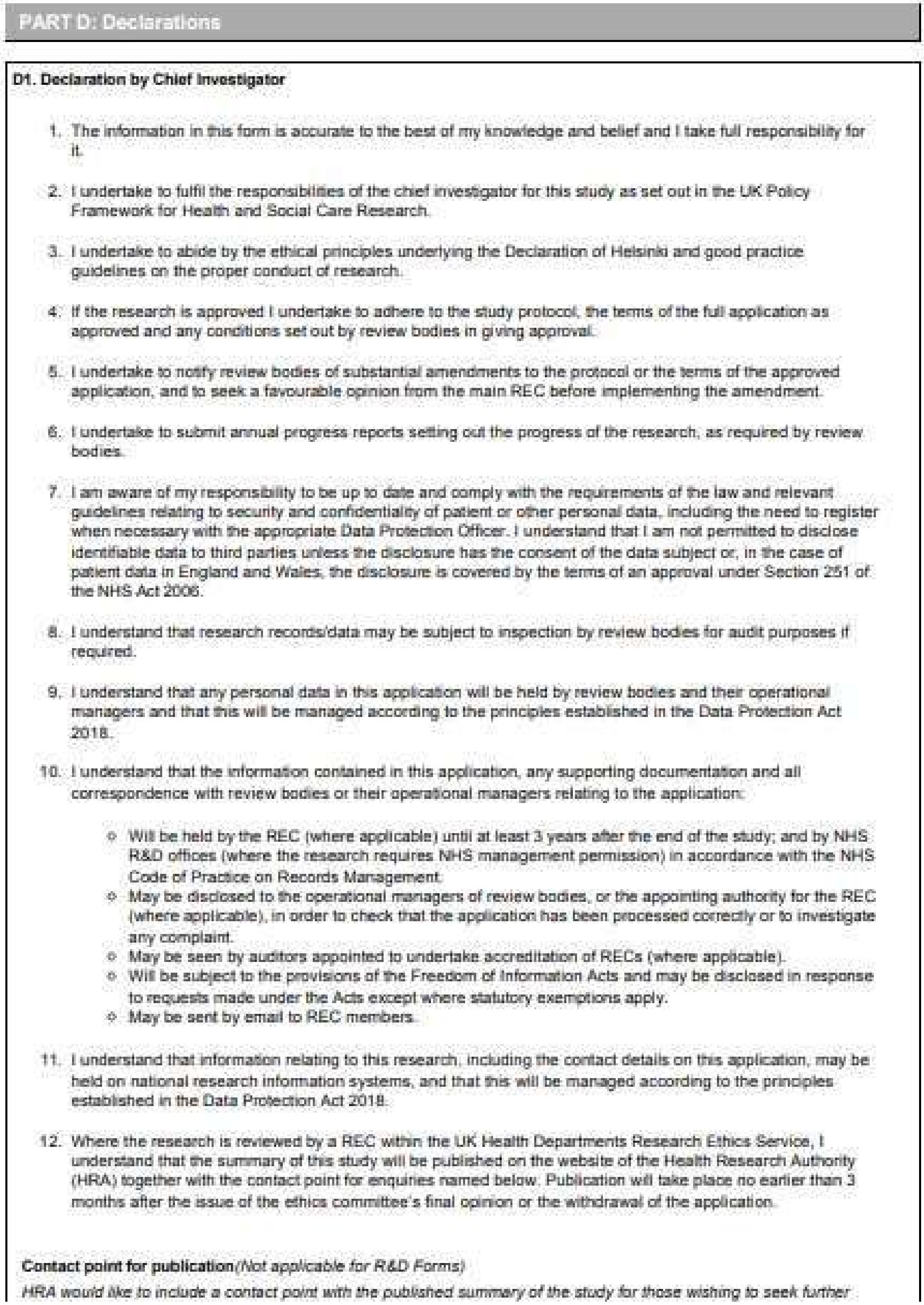


Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites. *For further information please refer to guidance.*

Investigator identifier	Research site	Investigator Name
IN2	● NHS/HSC Site ○ Non-NHS/HSC Site Organisation name Address Post Code Country [redacted]	Forename Middle name Family name Email Qualification (MD...) Country [redacted]
IN3	● NHS/HSC Site ○ Non-NHS/HSC Site Organisation name Address Post Code Country [redacted]	Forename Middle name Family name Email Qualification (MD...) Country [redacted]
IN4	○ NHS/HSC Site ● Non-NHS/HSC Site Institution name Lancaster University Department name Division of Health Research Street address Lancaster University Town/city Lancaster Post Code LA1 4YG	Forename Suzanne Middle name Family name Hodge Email s.hodge@lancaster.ac.uk Qualification (MD...) Lecturer in Health Research Country United Kingdom



Country	United Kingdom



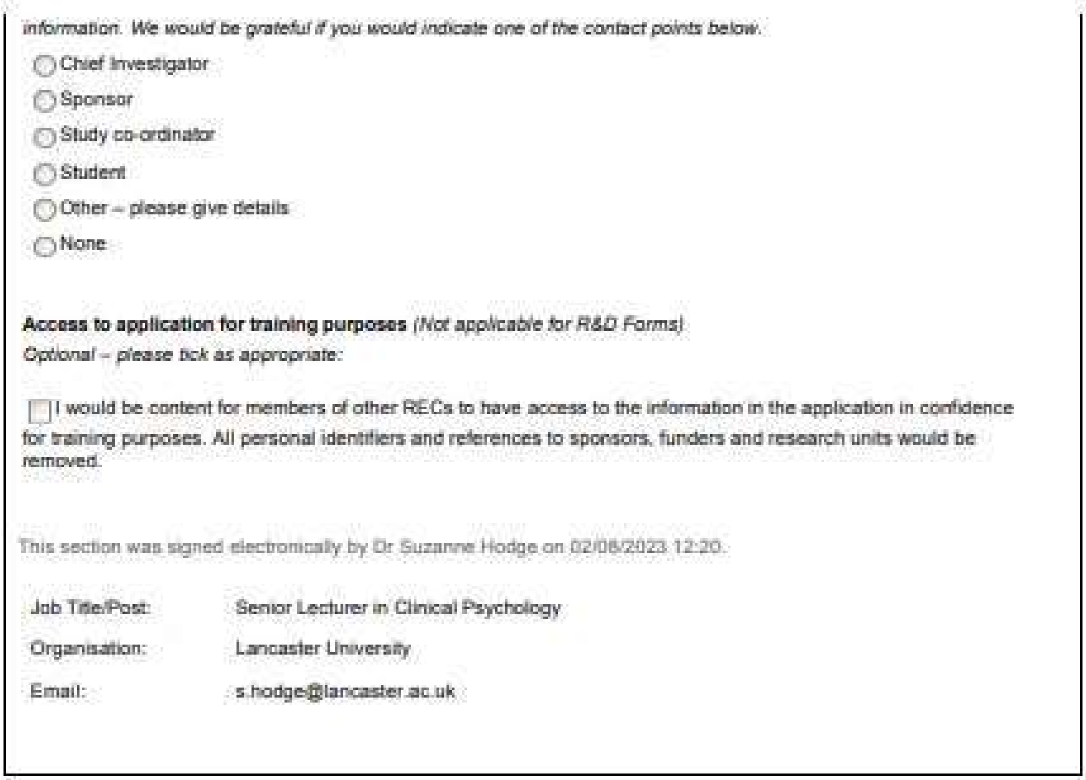
PART D: Declarations

D1. Declaration by Chief Investigator

1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.
2. I undertake to fulfil the responsibilities of the chief investigator for this study as set out in the UK Policy Framework for Health and Social Care Research.
3. I undertake to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research.
4. If the research is approved I undertake to adhere to the study protocol, the terms of the full application as approved and any conditions set out by review bodies in giving approval.
5. I undertake to notify review bodies of substantial amendments to the protocol or the terms of the approved application, and to seek a favourable opinion from the main REC before implementing the amendment.
6. I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.
7. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer. I understand that I am not permitted to disclose identifiable data to third parties unless the disclosure has the consent of the data subject or, in the case of patient data in England and Wales, the disclosure is covered by the terms of an approval under Section 251 of the NHS Act 2006.
8. I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.
9. I understand that any personal data in this application will be held by review bodies and their operational managers and that this will be managed according to the principles established in the Data Protection Act 2018.
10. I understand that the information contained in this application, any supporting documentation and all correspondence with review bodies or their operational managers relating to the application:
    - Will be held by the REC (where applicable) until at least 3 years after the end of the study; and by NHS R&D offices (where the research requires NHS management permission) in accordance with the NHS Code of Practice on Records Management.
    - May be disclosed to the operational managers of review bodies, or the appointing authority for the REC (where applicable), in order to check that the application has been processed correctly or to investigate any complaint.
    - May be seen by auditors appointed to undertake accreditation of RECs (where applicable).
    - Will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.
    - May be sent by email to REC members.
11. I understand that information relating to this research, including the contact details on this application, may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 2018.
12. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the Health Research Authority (HRA) together with the contact point for enquiries named below. Publication will take place no earlier than 3 months after the issue of the ethics committee's final opinion or the withdrawal of the application.

Contact point for publication*(Not applicable for R&D Forms)*

HRA would like to include a contact point with the published summary of the study for those wishing to seek further



information. We would be grateful if you would indicate one of the contact points below.

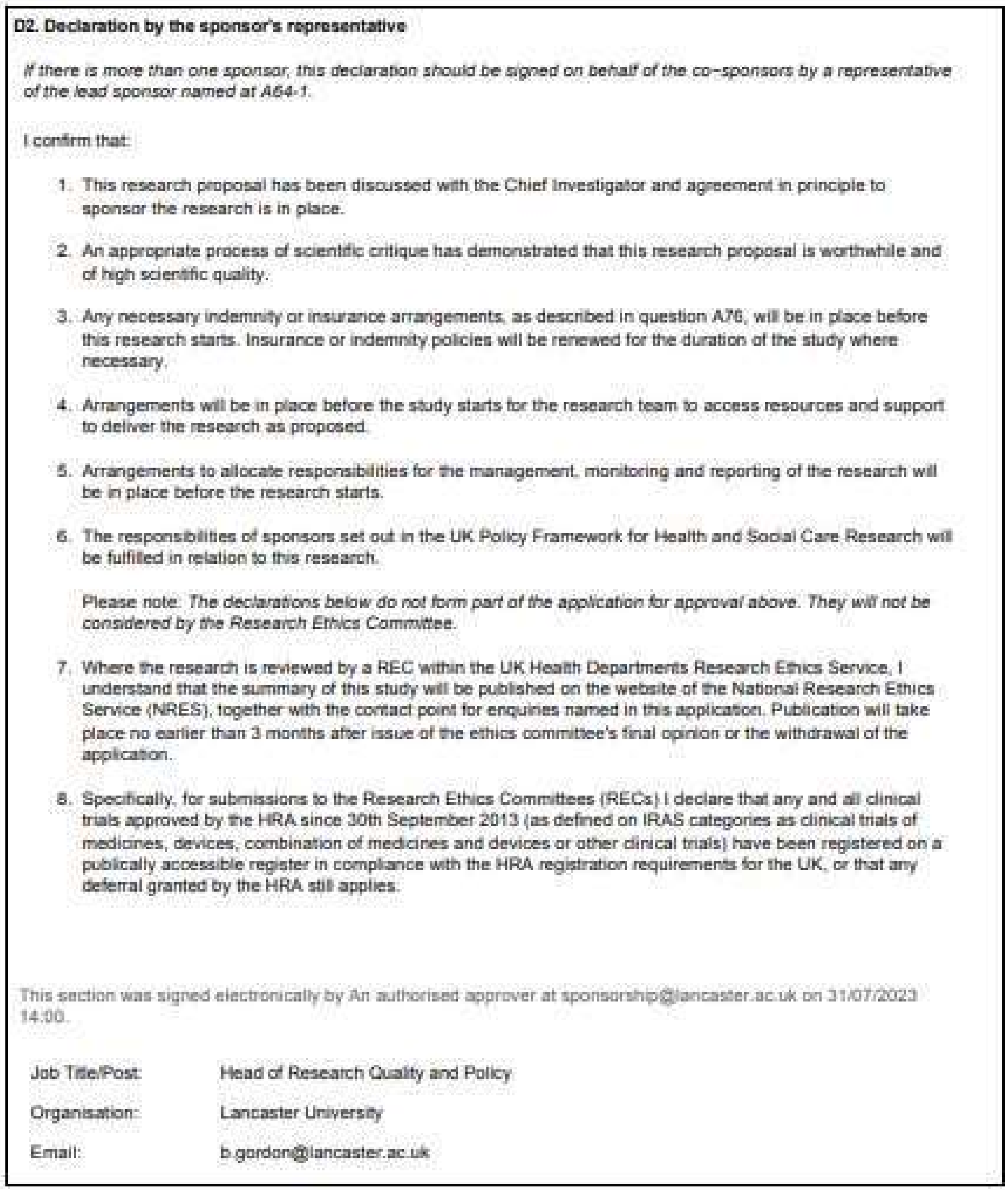
○ Chief Investigator
○ Sponsor
○ Study co-ordinator
○ Student
○ Other – please give details
○ None

Access to application for training purposes *(Not applicable for R&D Forms)*
Optional – please tick as appropriate:

☐ I would be content for members of other RECs to have access to the information in the application in confidence for training purposes. All personal identifiers and references to sponsors, funders and research units would be removed.

This section was signed electronically by Dr Suzanne Hodge on 02/08/2023 12:20.

Job Title/Post:	Senior Lecturer in Clinical Psychology
Organisation:	Lancaster University
Email:	s.hodge@lancaster.ac.uk



D2. Declaration by the sponsor's representative

If there is more than one sponsor, this declaration should be signed on behalf of the co-sponsors by a representative of the lead sponsor named at A64-1.

I confirm that:

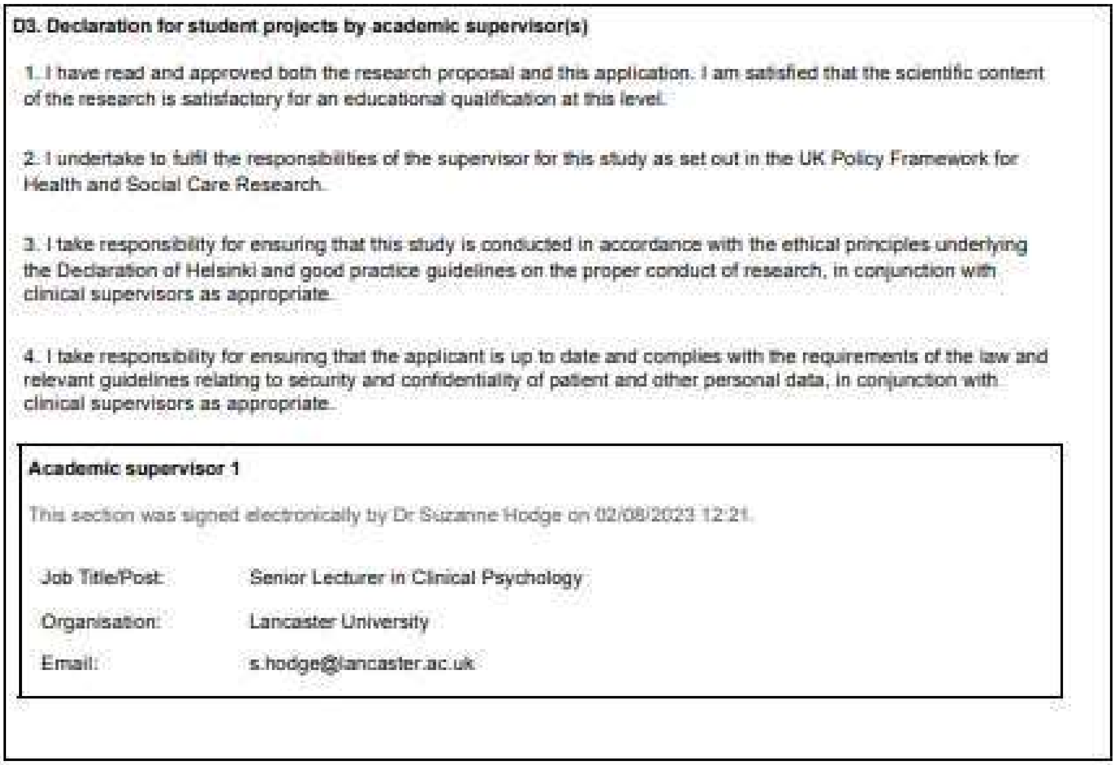
1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.
2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.
3. Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.
4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.
5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.
6. The responsibilities of sponsors set out in the UK Policy Framework for Health and Social Care Research will be fulfilled in relation to this research.

   Please note: *The declarations below do not form part of the application for approval above. They will not be considered by the Research Ethics Committee.*

7. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.
8. Specifically, for submissions to the Research Ethics Committees (RECs) I declare that any and all clinical trials approved by the HRA since 30th September 2013 (as defined on IRAS categories as clinical trials of medicines, devices, combination of medicines and devices or other clinical trials) have been registered on a publically accessible register in compliance with the HRA registration requirements for the UK, or that any deferral granted by the HRA still applies.

This section was signed electronically by An authorised approver at sponsorship@lancaster.ac.uk on 31/07/2023 14:00.

Job Title/Post:	Head of Research Quality and Policy
Organisation:	Lancaster University
Email:	b.gordon@lancaster.ac.uk



D3. Declaration for student projects by academic supervisor(s)

1. I have read and approved both the research proposal and this application. I am satisfied that the scientific content of the research is satisfactory for an educational qualification at this level.

2. I undertake to fulfil the responsibilities of the supervisor for this study as set out in the UK Policy Framework for Health and Social Care Research.

3. I take responsibility for ensuring that this study is conducted in accordance with the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research, in conjunction with clinical supervisors as appropriate.

4. I take responsibility for ensuring that the applicant is up to date and complies with the requirements of the law and relevant guidelines relating to security and confidentiality of patient and other personal data, in conjunction with clinical supervisors as appropriate.

Academic supervisor 1

This section was signed electronically by Dr Suzanne Hodge on 02/08/2023 12:21.

Job Title/Post:	Senior Lecturer in Clinical Psychology
Organisation:	Lancaster University
Email:	s.hodge@lancaster.ac.uk

Section Four Appendices

Appendix 1 Research Protocol

Appendix 2 Participant Information Sheet

Appendix 3 NHS Health Research Authority Approval Letter

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Appendix 1

Research Protocol

Title: Experiences of individuals with a diagnosis of Personality Disorder being diagnosed with Autism Spectrum Condition whilst in secondary mental health services.

Applicant: Jade Dalton

Research Supervisor: Dr Suzanne Hodge, Lecturer in Health Research, Doctorate in Clinical Psychology Programme, Lancaster University.

Field Supervisor: Dr Samantha McKenzie, Clinical Psychologist/Clinical Lead, Complex Emotional Needs Service, Humber NHS Foundation Trust.

Introduction

The National Institute for Health and Care Excellence (NICE) describes Autism Spectrum Condition (ASC) as a lifelong neurodevelopmental condition with a prevalence rate of 1% across the lifespan. The core features of ASC are described as "persistent difficulties in social interaction and communication and the presence of stereotypic behaviours, resistance to change or restricted interests" (NICE, 2012). Co-existing mental health difficulties have been found to affect individuals with ASC across the lifespan (Lai et al., 2019), with an estimated 70% of individuals with ASC experiencing at least one co-existing mental health condition (Hossain et al., 2020), a higher proportion than is observed within the general population (Lai et al., 2019). Changes in the diagnostic criteria for ASC within the Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-V)(American Psychiatric Association, 2013) have contributed to an increased number of adults being diagnosed with Autism in later life (Fusar-Poli et al., 2020) known as the 'lost generation' of autism.

One study exploring undiagnosed ASC reported that 75.4% of participants had their ASC missed during their first mental health evaluation, most of whom received treatment for a mental health condition (Gesi et al., 2021). The average time elapsed between initial mental health evaluation and a diagnosis of ASC for these individuals was 8 years. Individuals whose diagnosis of ASC was given later in life have described their diagnosis as empowering and improving their life through increased understanding of their difficulties (Leedham et al., 2019). Leedham et al. (2019) also report that receiving a diagnosis of ASC can help to reduce distress associated with mental health conditions.

Individuals who have a diagnosis or suspected diagnosis of ASC have been found to be more likely to disagree with their mental health diagnoses than individuals without ASC (Au-Yeung et al., 2018). Qualitative research has revealed that some females describe their comorbid diagnoses as misdiagnoses, and have experienced being misdiagnosed as detrimental to their wellbeing (Bargiela et al., 2016; Went, 2016).

Personality Disorder (PD) has been found to be one the most frequently occurring mental health conditions diagnosed within the ASC population (Fusar-Poli et al., 2020). The stigma surrounding diagnoses such as personality disorder Lamph et al., 2022; McKenzie et al., 2021) may influence the individual's decision to reject the diagnosis as a misdiagnosis upon receiving a later diagnosis of ASC, whilst clinicians may understand the two diagnoses as comorbidities. Mental health nurses were objectively rated as providing qualitatively poorer care, in the form of verbal responses, to people with Emotionally Unstable Personality Disorder (EUPD) than other patients (Fraser & Gallop, 1993). It could be argued that if the focus of the care for individuals with a diagnosis of PD who are later diagnosed with ASC was shifted from treating PD to treating ASC, the quality of the care and the relationship with the professional providing the care may be improved through decreased stigma.

NICE (2012) outline recommendations for treating co-existing mental health conditions for autistic adults within their autism clinical guidance. The guidelines outline that the co-occurring mental health disorders should be treated by following the associated NICE guidelines, with adaptations to make the intervention more accessible. Interventions such as dialectical behavioural therapy (DBT) and cognitive behavioural therapy (CBT) for OCD have been found to be effective for individuals with ASC Cornwall et al., 2021; Russell et al., 2008). Qualitative literature highlights, however, that this isn’t necessarily the experience of those with lived experience of receiving a diagnosis of ASC after an initial mental health diagnosis. Individuals described professionals involved in their care not believing they have ASC and therapy to treat the diagnosed mental health condition being ineffective (Went, 2016). Potential stigma from professionals may influence the individual’s perception of their treatment being suitably adapted to account for their new ASC diagnosis if the focus of the treatment remains as the initial PD diagnosis.

However, the relationship between PD stigma and the effect this has on care provided, and adapting treatment to account for ASC, has yet to be explored from the point of view of those receiving such care. This would be important to investigate for potential clinical implications into the care of individuals receiving care focussed on a diagnosis of PD who have later been diagnosed with ASC considering two factors: 1) how do individuals with a diagnosis of PD who are later diagnosed with ASC experience adaptations of their care related to their ASC diagnosis, and 2) do individuals with a diagnosis of PD who are later diagnosed with ASC experience a change in their relationship with mental health services post ASC diagnosis?

Method

Design

The study will employ a qualitative design. Semi-structured interviews will be conducted to gather participants' experiences of secondary mental health services following a diagnosis of ASC having previously received a diagnosis of PD. The use of semi-structured interviews will allow discussions to be structured whilst facilitating flexibility for the participants' experiences to inform the direction of the interviews.

Interviews will be transcribed by the researcher verbatim and will then be analysed using Interpretive Phenomenological Analysis (IPA). As the research aims to explore participants' lived experiences, how they made sense of their experiences, and the meaning they attach to the experiences, IPA has been chosen as the most appropriate method of analysis due to its focus on how individuals understand and make sense of their lived experiences.

Participants

Participants will be people who received an initial diagnosis of personality disorder from mental health services and were later diagnosed with autism spectrum condition. The ASC diagnosis will have been received in the last 5 years; this timeframe has been chosen to allow for a good enough memory of their experiences of mental health services since the diagnosis.

The study will recruit participants aged 18 and above, who were 18 or above at the time of receiving a diagnosis of personality disorder. Though personality disorders can be diagnosed in adolescents, there is disagreement amongst professionals regarding the validity and ethical considerations of this (Kaess et al., 2014). We will aim to recruit a minimum of 8 and a maximum of 12 participants for the who will be selected based on the study's inclusion and exclusion criteria.

Participants will be recruited via NHS secondary mental health services. Potential participants will receive a screening questionnaire asking their age, when they received their PD diagnosis, when they received this ASC diagnosis, from whom they received each diagnosis, and which type of secondary mental health service they were under at the time of their ASC diagnosis. Screening questionnaires will be completed by a clinician involved in the potential participants care e.g. care coordinator alongside the potential participant. This will ensure that the participants recruited meet the inclusion criteria.

Participants will also be recruited from the general population via advertising on social media, including X (Twitter), Facebook, Instagram, Threads, and Reddit. Participants recruited via social media will receive a screening questionnaire asking their age, when they received their PD diagnosis, when they received this ASC diagnosis, from whom they received each diagnosis, and which type of secondary mental health service they were under at the time of their ASC diagnosis. Screening questionnaires will be completed by the potential participant and emailed to the researcher. This will ensure that the participants recruited meet the inclusion criteria.

Inclusion Criteria:

- The individual's first diagnosis was PD
- The individual's PD diagnosis was given when they were at least 18 years of age
- The individual is aged 18 and above
- The individual is able to speak and understand English

- The individual received a diagnosis of ASC after being given a diagnosis of PD
- The individual received a diagnosis of ASC within the last 5 years
- The individual was in secondary mental health services at the time their ASC diagnosis was given
- Both the PD and the ASC diagnoses are formal diagnoses given by mental health professionals and are not self-diagnosed

Exclusion Criteria

- The individual's diagnosis of a PD was given after their diagnosis of ASC
- The individual's diagnosis of a PD was given before they were 18 years of age
- The individual is not aged 18 and above
- The individual is not able to speak or understand English
- The individual was not in secondary mental health services at the time of the ASC diagnosis
- The individual received an ASC diagnoses more than 5 years ago
- The individual's PD or ASC is self-diagnosed
- Individuals within inpatient settings due to their environment being a potential confounding variable and the possibility of increased risk

Design

A qualitative design will be employed for this study. Individual semi-structured interviews will be conducted with participants. Semi-structured interviews will be used as an appropriate method to collect qualitative data that guides the discussion without limiting the questions to what the researcher thinks is important to ask and reducing researcher bias, allowing the participants to steer the conversations towards what it is important for them to discuss about their experiences. Interviews will be offered face to face, remotely via video conference (Microsoft Teams), and by telephone to increase accessibility.

Verbatim transcriptions of the interviews will be produced by the Student Researcher. As the research aims to explore participants' lived experiences, how they made sense of their experiences, and the meaning they attach to the experiences, Interpretive Phenomenological Analysis (IPA) has been chosen as the most appropriate method of analysis due to its focus on how individuals understand and make sense of their lived experiences.

Materials

A participant information sheet will be provided to each participant, as well as a consent form. A screening questionnaire will be used to assess participant eligibility.

Semi-structured interview schedules and audio recorder will be available to the Student Researcher during the interviews.

Procedure

Recruitment

Secondary mental health services in [REDACTED] will be approached to advertise the study via placing posters in their services and giving participant information sheets to service users who meet the inclusion criteria. The research will also be advertised on social media to allow participation from those who are no longer accessing mental health services.

Social media outlets will include Facebook, X (Twitter), Instagram, Threads, and Reddit.

Potential participants who are interested in taking part in the study will be able to contact the Student Researcher for further information by telephone or email via the research poster. Potential participants will then be asked to give verbal consent to completing the screening questionnaire, and responses will be considered in line with the study's inclusion and exclusion criteria. Screening questionnaires will be completed by a clinician involved in the potential participants care e.g. care coordinator alongside the potential participant for those recruited via NHA site, or by the participant themselves if recruited via social media, and emailed to the student researcher. Emails containing participant information will be sent via a secure NHS email process by encrypting the emails. If the responses to the demographic questionnaire satisfy these criteria, participants will be invited to arrange a suitable interview date, time, and format.

Interviews will begin with the Student Researcher going through the participant information sheet and obtaining informed consent via the consent form prior to interviews.

Data Collection

Following the recruitment phase participants will be asked to attend an interview session that will last approximately 1 hour. Participants will be asked to read and sign the consent form which will be emailed securely to the student researcher, completed by a clinician involved in their care for participants recruited via the NHS.

Talking through the participant information sheet and revisiting consent via the consent form will take approximately 10 minutes prior to the interview. Participants' confidentiality and right to withdraw will also be outlined during this time, including their right to decline to answer any questions that may cause them distress during the interview. Participants will be offered the opportunity to ask any further questions they may have about participating in the study before consent is obtained.

If participants become distressed during the interview opportunities will be given to take a break, discontinue the interview, or arrange to continue to interview at a later date.

Once the interview is complete participants will be debriefed and will have an opportunity to ask any further questions they may have about the study. Participants will also be directed to the support available outlined within the distress protocol at this time.

Analysis

All the interviews conducted within this study will be recorded using an audio recorder and will be transcribed verbatim by the Student Researcher. An Interpretive

Phenomenological Analysis approach will be used to analyse the data. Data will be analysed line by line, emergent patterns will be identified, a dialogue between the data, the researcher, and the researcher's psychological knowledge will be developed, and relationships between themes will be illustrated (Smith et al., 2009). Transcripts will be analysed one by one, in keeping with the ideographic element of IPA. A narrative including commentary on data extracts and the researcher's reflections will then be produced, aided by the use of a reflective journal throughout the process.

Practical Issues

The recordings of the interviews will be stored on a password protected space within the Student Researcher's university OneDrive cloud-based storage space as soon after they are recorded as possible. Once the recording has been transferred to the OneDrive the recording on the audio recorder will be deleted by the Student Researcher. Interview transcripts will also be stored securely on the university's OneDrive cloud-based storage space. Once transcripts are obtained, recordings of interviews will be destroyed.

Hard copies of materials containing participant information will be stored securely in a locked cabinet in a secure office and will only be accessible by the Student Researcher. Hard copies will be scanned onto the university computer system and encrypted and stored as electronic data before being destroyed by the Student Researcher.

Ethical Concerns

There are no identified risks to participants who chose to participate in this study. However, some participants may find discussing their time in secondary mental health services distressing. If participants become distressed during the interview, the Student Researcher will offer the opportunity to pause or end the interview. Opportunities to take a break during the interview and reminders of participants' right to withdraw from the study will also be given to participants who become distressed. The participant information sheet will contain information regarding where the participants can seek further support following their participation in the study should they so wish.

Participants are able to withdraw from the study at any time. However, as outlined within the consent form, removal of participant data is limited to two weeks after their participation in the interview. After this time, as data may have been pooled and analysis commenced, it may not be possible to identify and remove individual participant data.

Limits of confidentiality and anonymity will be discussed with participants at the start of the interviews, with this information being included in the consent forms and participant information sheets. This will include reminding participants that the researcher may need to break confidentiality should they disclose anything within the interview that suggests there may be a risk of harm to themselves or others. If the Student researcher needs to break confidentiality at any point during the study this will be discussed with the participant and the appropriate safeguarding procedures will be followed.

Risk to Researchers

For recruitment purposes participants will require access to the Student Researcher’s email address. The Student Researcher’s university email address will be used for all correspondence with participants to mitigate any potential risks. A telephone number specific to the study will also be used for communication with participants rather than the Student Researcher’s personal telephone number.

Interviews will be offered face to face, via Microsoft Teams, and via telephone depending on the geographical location of the participants and any accessibility issues that may need consideration on an individual basis. An appropriate space within an NHS service will be accessed for any participants who are recruited via NHS recruitment. The Chief Investigator will be aware of the date, time, and location of all interviews and the university's lone working policy will be adhered to.

Timescale

Submit ethics proposal – August 2023

Data collection – October - December 2023

Data analysis – January – February 2024

Submit thesis – March 2024

End of study – Upon student researcher passing the Viva associated with the study, approximately August 2024.

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[Unpublished Doctoral Dissertation, University of Exeter].

https://guides.library.uq.edu.au/referencing/apa7/thesis#s-lg-box-21144101

Appendix 2

Participant Information Sheet

Participant Information Sheet

Experiences of individuals with a diagnosis of Personality Disorder being diagnosed with Autism Spectrum Condition whilst in secondary mental health services.

For further information about how Lancaster University processes personal data for research purposes and your data rights please visit our webpage: www.lancaster.ac.uk/research/dataprotection

My name is Jade, and I am conducting this research as a student in the Doctorate in Clinical Psychology programme at Lancaster University, Lancaster, United Kingdom, and the project is sponsored by Lancaster University. This information sheet will provide you with some information about the research project; please read this information carefully and use it to help you decide whether you would like to take part. Details of how you can contact me with any further questions can be found towards the end of the sheet.

What is the study about?

The purpose of this study is to explore the experiences of people who have received a diagnosis of Autism Spectrum Condition after a previous diagnosis of a Personality Disorder during their time in secondary mental health services.

Why have I been approached?

You have been approached because you have expressed interest in taking part in the study and are someone who has received a diagnosis of Autism Spectrum Condition (ASC) after having received a diagnosis of Personality Disorder (PD), at a time you were being supported by secondary mental health services.

Do I have to take part?

No. It's completely up to you to decide whether or not you take part, and you can withdraw from the study at any time without affecting any medical care you are receiving.

What will I be asked to do if I take part?

If you decide you would like to take part, you would be asked to complete a short screening questionnaire, administered by somebody involved in your care if you have expressed interest via an NHS service, to make sure that you meet the criteria to take part.

You will then be asked to take part in a 60 minute interview with the researcher which can be online, by telephone, or in person depending on your location with a person of your choice accompanying you if you wish for your comfort and safety. Online interviews will be conducted via Microsoft Teams, and you will have the option to turn your camera off whilst the interview is being recorded. Travel expenses to interview locations cannot be reimbursed. The interview will explore your experiences of secondary mental health services related to your ASC and PD diagnoses. Confidentiality and consent will be discussed prior to the interview starting and we will revisit some of the information on this sheet.

The interviews will be recorded and then written up by the researcher. You will have an opportunity to pick a pseudonym for the write up of your interview to keep you anonymous.

Will my data be Identifiable?

- The data collected for this study will be stored securely on university approved cloud storage, and only the researchers conducting this study will have access to this.
- Audio recordings will be destroyed and/or deleted once the transcriptions are completed.
- Hard copies of questionnaires will be kept in a locked cabinet, and at the end of the study they will be scanned onto the university computer system. Hard copies will then be destroyed.
- The files on the computer will be encrypted (that is no-one other than the researcher will be able to access them) and the computer itself password protected.
- The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them. All reasonable steps will be taken to protect the anonymity of the participants involved in this project.
- All your personal data will be confidential and will be kept separately from your interview responses.

There are some limits to confidentiality: if what is said in the interview makes the researcher think that you, or someone else, is at significant risk of harm, the researcher will have to break confidentiality and speak to a member of staff about this. If possible, the researcher will tell you if they have to do this.

Should you lose capacity to consent to participate in the study at any time any information obtained prior to this will be retained and stored anonymously.

Lancaster University will be the data controller for any personal information collected as part of this study. Under the GDPR you have certain rights when personal data is collected about you. You have the right to access any personal data held about you, to object to the processing of your personal information, to rectify personal data if it is inaccurate, the right to have data about you erased and, depending on the circumstances, the right to data portability. Please be aware that many of these rights are not absolute and only apply in certain circumstances. If you would like to know more about your rights in relation to your personal data, please speak to the researcher on your particular study.

For further information about how Lancaster University processes personal data for research purposes and your data rights please visit our webpage: www.lancaster.ac.uk/research/data-protection

Lancaster University Information Governance Manager
Michael Abbotts: michael.abbotts@lancaster.ac.uk

What if I change my mind?

You can decide to withdraw from the study at any time and you can ask for your data to be removed from the study up to 2 weeks after the interview.

What will happen to the results?

The results will be summarised and reported in a thesis and may be submitted for publication in an academic or professional journal and may also be presented at conferences.

An accessible easy read infographic or poster will also be made outlining the main results of the study.

If you would like a copy of the final study or the infographic/poster, please email the researcher using the contact details below.

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress following participation there are details of some support services that you can contact at the end of this sheet.

Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part. It is hoped that taking part in this study will give you an opportunity to have you voice heard in relation to your experiences in secondary mental health services.

Who has reviewed the project?

This study has been reviewed and approved by the Health Research Authority; and received favourable opinion from ref: 23/YH/0192

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the main researchers:

Lead Researcher: Jade Dalton – j.dalton6@lancaster.ac.uk
Chief Investigator: Suzanne Hodge (research supervisor) – s.hodge@lancaster.ac.uk

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researchers, you can contact:

Professor Bill Sellwood
Programme Director of the Doctorate in Clinical Psychology
Faculty of Health and Medicine
Lancaster University
Tel: +44 (0)1524 593998

Email: b.sellwood@lancaster.ac.uk

If you wish to speak to someone outside of the Lancaster Doctorate Programme, you may also contact:

Dr Laura Machin
Chair of FHM REC
Faculty of Health and Medicine
(Lancaster Medical School)
Lancaster University
Lancaster
LA1 4YG
Tel: +44 (0)1524 594973
Email: l.machin@lancaster.ac.uk

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

Resources in the event of distress

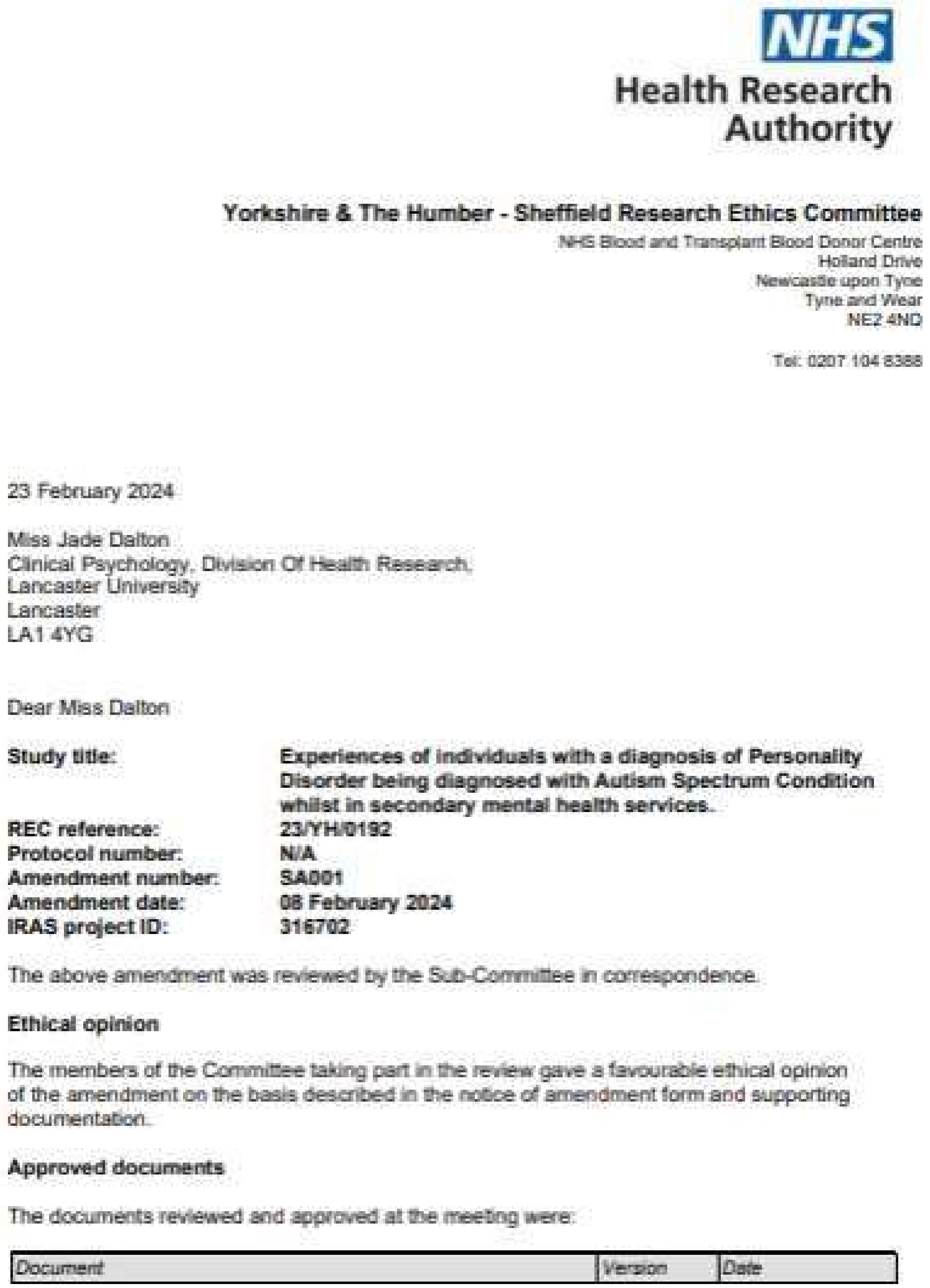
Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance: o Any mental health services you are currently accessing o Your GP o The Samaritans their 24 hour helpline (116 123) or website www.samaritans.org o Mind on the following number (Monday to Friday, 9am to 6pm): 0300 123 3393, or by email on: info@mind.org.uk or by text message on: 86463

Thank you for taking the time to read this information sheet.
If you have read this information and would like to take part in the research, please contact the lead researcher, Jade Dalton:

j.dalton6@lancaster.ac.uk

Appendix 3

NHS Health Research Authority Approval Letter



NHS
Health Research
Authority

Yorkshire & The Humber - Sheffield Research Ethics Committee
NHS Blood and Transplant Blood Donor Centre
Holland Drive
Newcastle upon Tyne
Tyne and Wear
NE2 4NQ

Tel: 0207 104 8388

23 February 2024

Miss Jade Dalton
Clinical Psychology, Division Of Health Research,
Lancaster University
Lancaster
LA1 4YG

Dear Miss Dalton

Study title:	**Experiences of individuals with a diagnosis of Personality Disorder being diagnosed with Autism Spectrum Condition whilst in secondary mental health services.**
REC reference:	**23/YH/0192**
Protocol number:	**N/A**
Amendment number:	**SA001**
Amendment date:	**08 February 2024**
IRAS project ID:	**316702**

The above amendment was reviewed by the Sub-Committee in correspondence.

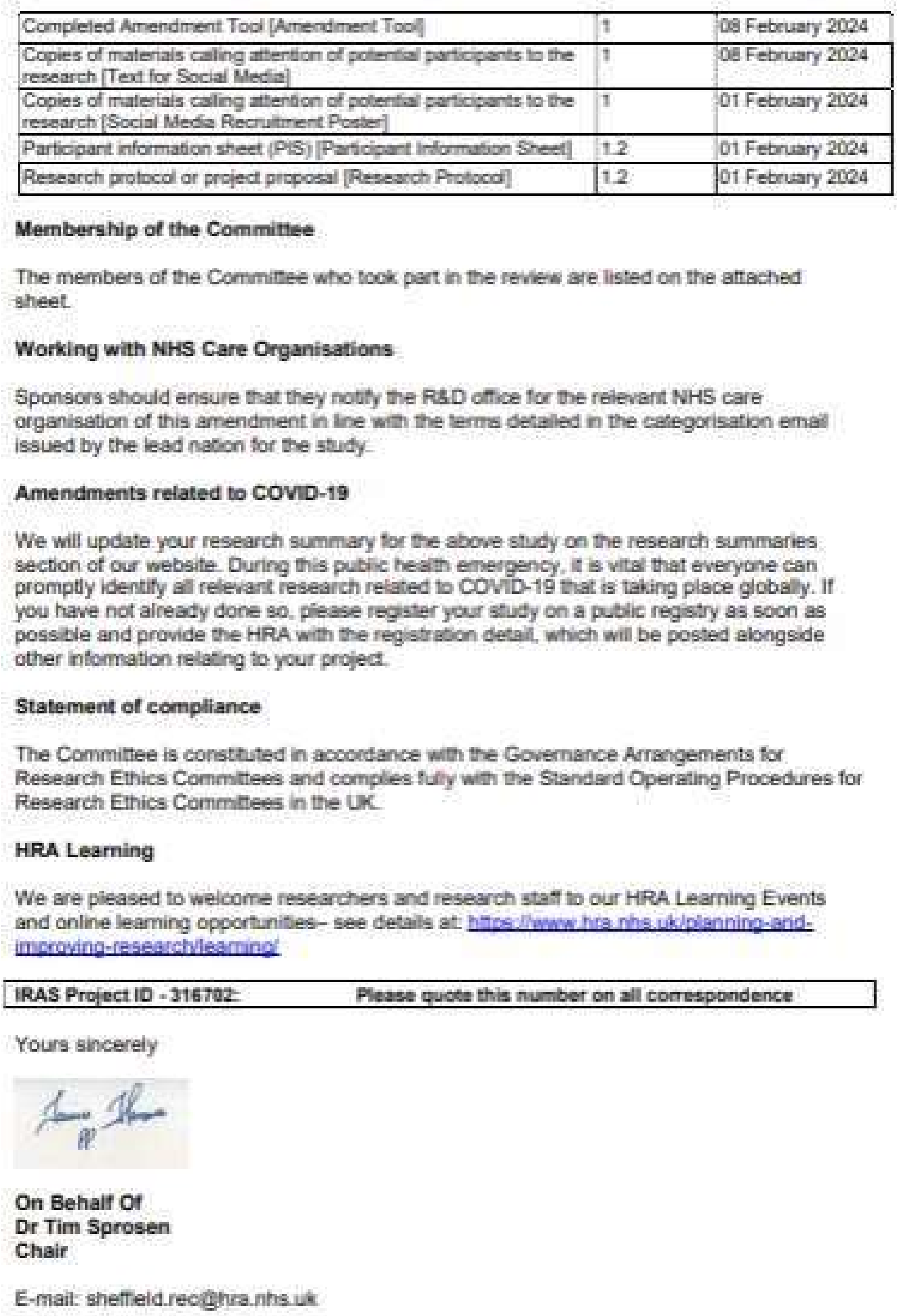
Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*



Completed Amendment Tool [Amendment Tool]	1	08 February 2024
Copies of materials calling attention of potential participants to the research [Text for Social Media]	1	08 February 2024
Copies of materials calling attention of potential participants to the research [Social Media Recruitment Poster]	1	01 February 2024
Participant information sheet (PIS) [Participant Information Sheet]	1.2	01 February 2024
Research protocol or project proposal [Research Protocol]	1.2	01 February 2024

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Amendments related to COVID-19

We will update your research summary for the above study on the research summaries section of our website. During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you have not already done so, please register your study on a public registry as soon as possible and provide the HRA with the registration detail, which will be posted alongside other information relating to your project.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS Project ID - 316702: **Please quote this number on all correspondence**

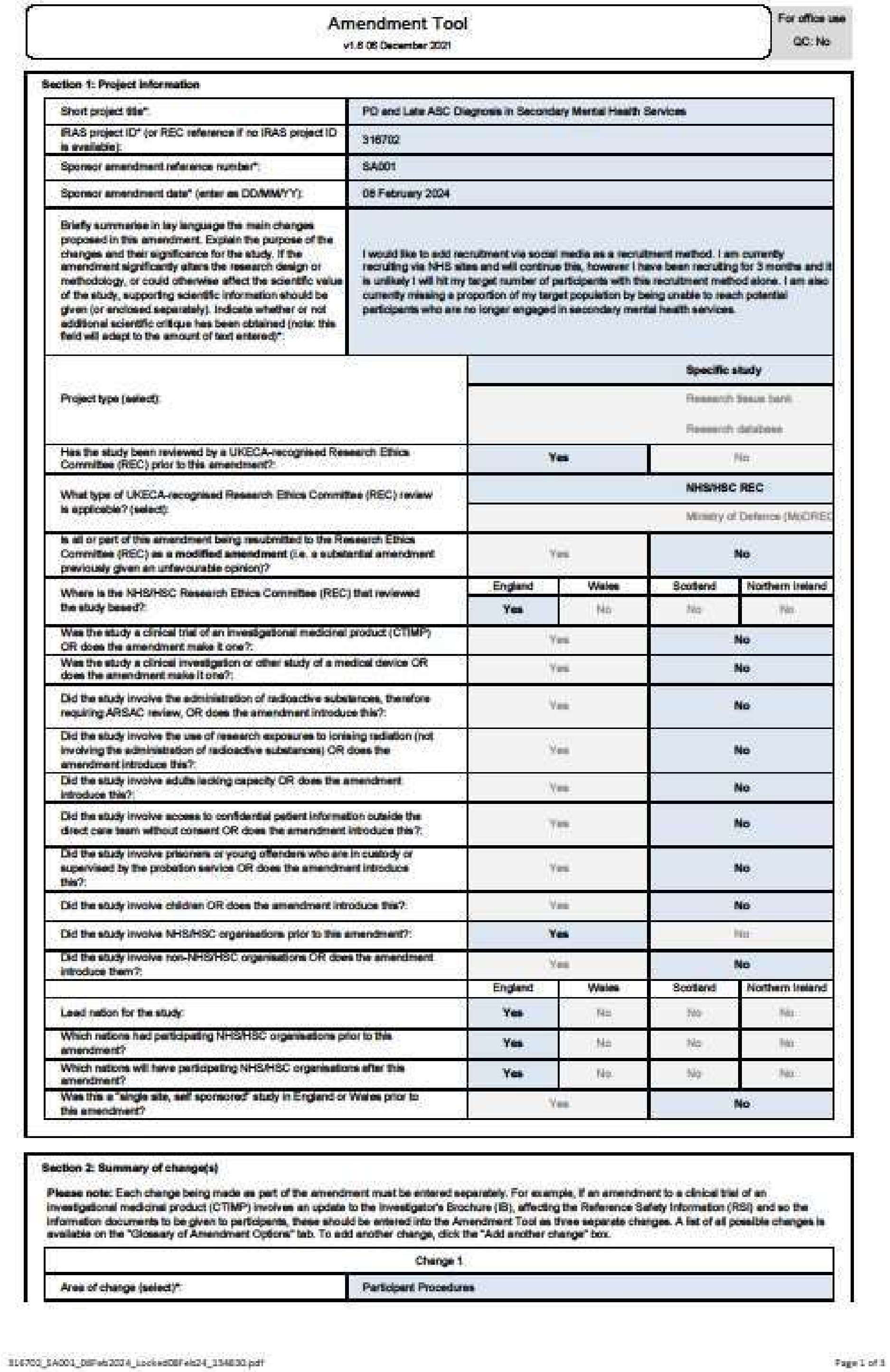
Yours sincerely

On Behalf Of
Dr Tim Sprosen
Chair

E-mail: sheffield.rec@hra.nhs.uk

Appendix 4

Integrated Research Application System Amendment



Amendment Tool

v1.6 06 December 2021

For office use
QC: No

Section 1: Project information

Short project title*:	PD and Late ASC Diagnosis in Secondary Mental Health Services			
IRAS project ID* (or REC reference if no IRAS project ID is available):	316702			
Sponsor amendment reference number*:	SA001			
Sponsor amendment date* (enter as DD/MM/YY):	08 February 2024			
Briefly summarise in lay language the main changes proposed in this amendment. Explain the purpose of the changes and their significance for the study. If the amendment significantly alters the research design or methodology, or could otherwise affect the scientific value of the study, supporting scientific information should be given (or enclosed separately). Indicate whether or not additional scientific critique has been obtained (note: this field will adapt to the amount of text entered)*:	I would like to add recruitment via social media as a recruitment method. I am currently recruiting via NHS sites and will continue this, however I have been recruiting for 3 months and it is unlikely I will hit my target number of participants with this recruitment method alone. I am also currently missing a proportion of my target population by being unable to reach potential participants who are no longer engaged in secondary mental health services.			
Project type (select):	**Specific study** Research tissue bank Research database			
Has the study been reviewed by a UKECA-recognised Research Ethics Committee (REC) prior to this amendment?:	**Yes**		No	
What type of UKECA-recognised Research Ethics Committee (REC) review is applicable? (select):	**NHS/HSC REC** Ministry of Defence (MoDREC			
Is all or part of this amendment being resubmitted to the Research Ethics Committee (REC) as a **modified amendment** (i.e. a substantial amendment previously given an unfavourable opinion)?	Yes		**No**	
Where is the NHS/HSC Research Ethics Committee (REC) that reviewed the study based?:	England	Wales	Scotland	Northern Ireland
	Yes	No	No	No
Was the study a clinical trial of an investigational medicinal product (CTIMP) OR does the amendment make it one?:	Yes		**No**	
Was the study a clinical investigation or other study of a medical device OR does the amendment make it one?:	Yes		**No**	
Did the study involve the administration of radioactive substances, therefore requiring ARSAC review, OR does the amendment introduce this?:	Yes		**No**	
Did the study involve the use of research exposures to ionising radiation (not involving the administration of radioactive substances) OR does the amendment introduce this?:	Yes		**No**	
Did the study involve adults lacking capacity OR does the amendment introduce this?:	Yes		**No**	
Did the study involve access to confidential patient information outside the direct care team without consent OR does the amendment introduce this?:	Yes		**No**	
Did the study involve prisoners or young offenders who are in custody or supervised by the probation service OR does the amendment introduce this?:	Yes		**No**	
Did the study involve children OR does the amendment introduce this?:	Yes		**No**	
Did the study involve NHS/HSC organisations prior to this amendment?:	**Yes**		No	
Did the study involve non-NHS/HSC organisations OR does the amendment introduce them?:	Yes		**No**	
	England	Wales	Scotland	Northern Ireland
Lead nation for the study:	**Yes**	No	No	No
Which nations had participating NHS/HSC organisations prior to this amendment?	**Yes**	No	No	No
Which nations will have participating NHS/HSC organisations after this amendment?	**Yes**	No	No	No
Was this a "single site, self sponsored" study in England or Wales prior to this amendment?	Yes		**No**	

Section 2: Summary of change(s)

Please note: Each change being made as part of the amendment must be entered separately. For example, if an amendment to a clinical trial of an investigational medicinal product (CTIMP) involves an update to the Investigator's Brochure (IB), affecting the Reference Safety Information (RSI) and so the information documents to be given to participants, these should be entered into the Amendment Tool as three separate changes. A list of all possible changes is available on the "Glossary of Amendment Options" tab. To add another change, click the "Add another change" box.

Change 1	
Area of change (select)*:	Participant Procedures

316702_SA001_08Feb2024_Locked08Feb24_134830.pdf

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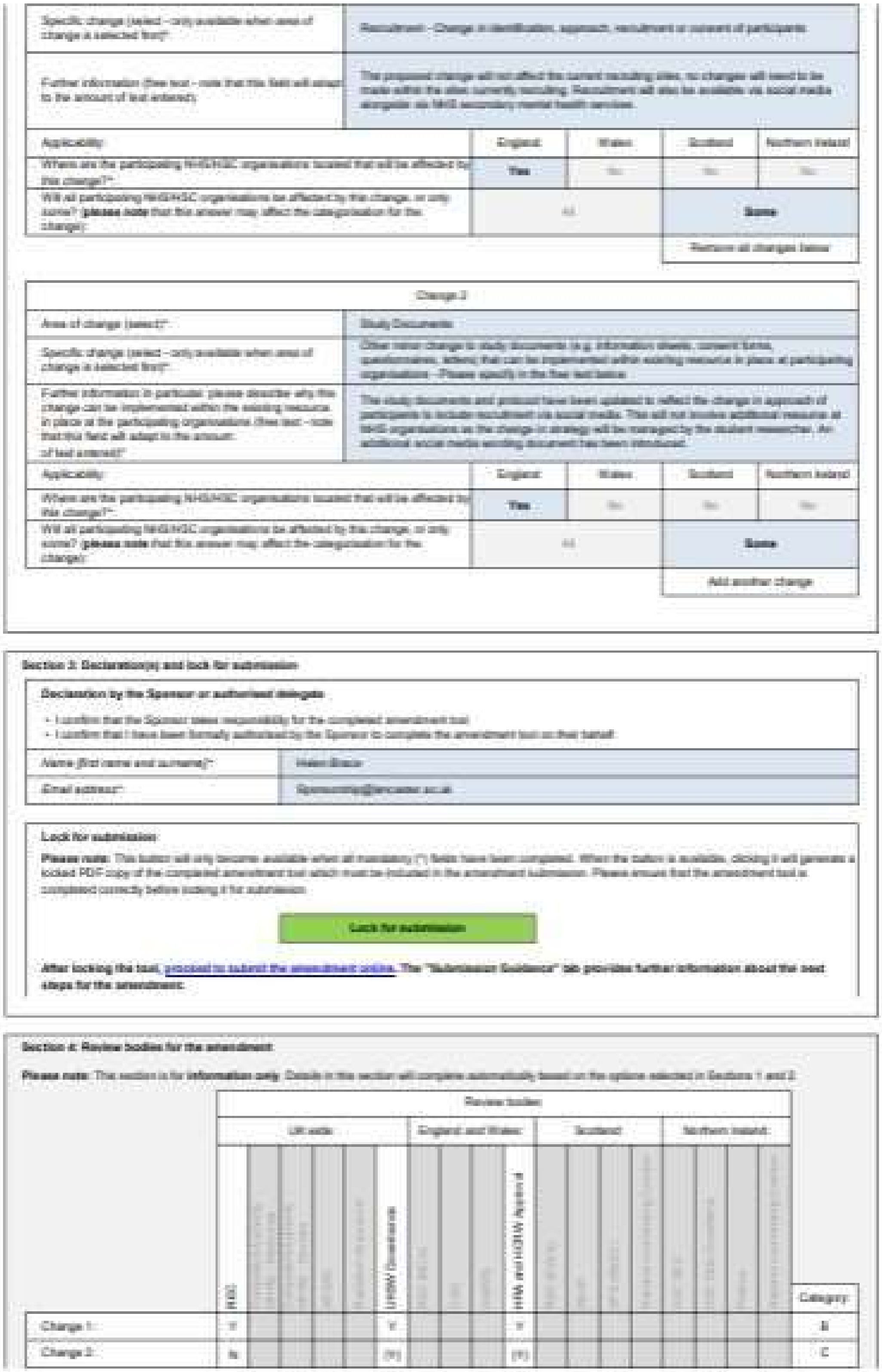


Specific change (select – only available when area of change is selected first)*	Recruitment - Change in identification, approach, recruitment or consent of participants				
Further information (free text – note that this field will adapt to the amount of text entered)	The proposed change will not affect the current recruiting sites, no changes will need to be made within the sites currently recruiting. Recruitment will also be available via social media alongside via NHS secondary mental health services.				
Applicability:		England	Wales	Scotland	Northern Ireland
Where are the participating NHS/HSC organisations located that will be affected by this change?*		Yes	No	No	No
Will all participating NHS/HSC organisations be affected by the change, or only some? (**please note** that this answer may affect the categorisation for the change):		All		Some	

Remove all changes below

Change 2					
Area of change (select)*:	Study Documents				
Specific change (select – only available when area of change is selected first)*:	Other minor change to study documents (e.g. information sheets, consent forms, questionnaires, letters) that can be implemented within existing resource in place at participating organisations - Please specify in the free text below				
Further information In particular, please describe why the change can be implemented within the existing resource in place at the participating organisations (free text – note that this field will adapt to the amount of text entered)*	The study documents and protocol have been updated to reflect the change in approach of participants to include recruitment via social media. This will not involve additional resource at NHS organisations as the change in strategy will be managed by the student researcher. An additional social media wording document has been introduced.				
Applicability:		England	Wales	Scotland	Northern Ireland
Where are the participating NHS/HSC organisations located that will be affected by this change?*		Yes	No	No	No
Will all participating NHS/HSC organisations be affected by the change, or only some? (**please note** that this answer may affect the categorisation for the change):		All		Some	

Add another change

Section 3: Declaration(s) and lock for submission

Declaration by the Sponsor or authorised delegate

- I confirm that the Sponsor takes responsibility for the completed amendment tool
- I confirm that I have been formally authorised by the Sponsor to complete the amendment tool on their behalf

Name (first name and surname):*	[illegible]
Email address:*	Sponsorship@lancaster.ac.uk

Lock for submission:

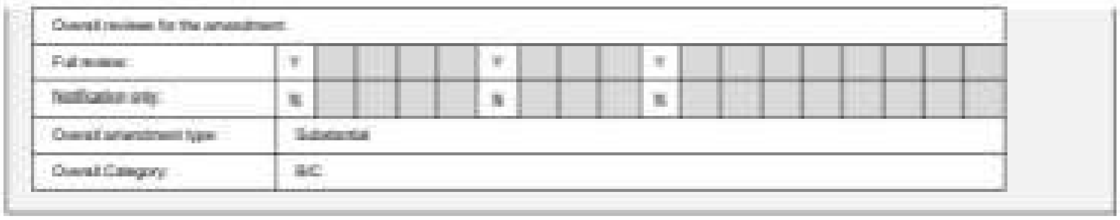
Please note: This button will only become available when all mandatory (*) fields have been completed. When the button is available, clicking it will generate a locked PDF copy of the completed amendment tool which must be included in the amendment submission. Please ensure that the amendment tool is completed correctly before locking it for submission.

After locking the tool, proceed to submit the amendment online. The "Submission Guidance" tab provides further information about the next steps for the amendment.

Section 4: Review bodies for the amendment

Please note: This section is for **information only**. Details in this section will complete automatically based on the options selected in Sections 1 and 2.

	Review bodies																		
	UK wide						England and Wales				Scotland				Northern Ireland				
	REC					[illegible] Governance				HRA and HCRW Approval									Category
Change 1:	Y					Y				Y									B
Change 2:	N					(Y)				(Y)									C



Overall reviews for the amendment:																		
Full review:	Y					Y				Y								
Notification only:	N					N				N								
Overall amendment type:	Substantial																	
Overall Category:	B/C																	

Favourable Opinion Letter – IRAS Amendments

NHS
Health Research
Authority

Yorkshire & The Humber - Sheffield Research Ethics Committee
NHS Blood and Transplant Blood Donor Centre
Holland Drive
Newcastle upon Tyne
Tyne and Wear
NE2 4NQ

Tel: 0207 104 8388

23 February 2024

Miss Jade Dalton
Clinical Psychology, Division Of Health Research,
Lancaster University
Lancaster
LA1 4YG

Dear Miss Dalton

Study title:	**Experiences of individuals with a diagnosis of Personality Disorder being diagnosed with Autism Spectrum Condition whilst in secondary mental health services.**
REC reference:	**23/YH/0192**
Protocol number:	**N/A**
Amendment number:	**SA001**
Amendment date:	**08 February 2024**
IRAS project ID:	**316702**

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*

Completed Amendment Tool [Amendment Tool]	1	08 February 2024
Copies of materials calling attention of potential participants to the research [Text for Social Media]	1	08 February 2024
Copies of materials calling attention of potential participants to the research [Social Media Recruitment Poster]	1	01 February 2024
Participant information sheet (PIS) [Participant Information Sheet]	1.2	01 February 2024
Research protocol or project proposal [Research Protocol]	1.2	01 February 2024

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Amendments related to COVID-19

We will update your research summary for the above study on the research summaries section of our website. During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you have not already done so, please register your study on a public registry as soon as possible and provide the HRA with the registration detail, which will be posted alongside other information relating to your project.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS Project ID - 316702: **Please quote this number on all correspondence**

Yours sincerely

On Behalf Of
Dr Tim Sprosen
Chair

E-mail: sheffield.rec@hra.nhs.uk

Appendix 6

Participant Consent Form

CONSENT FORM

Experiences of individuals with a diagnosis of Personality Disorder being diagnosed with Autism Spectrum Condition whilst in secondary mental health services.

Name of Researcher: Jade Dalton

Email: j.dalton@lancaster.ac.uk

Name of Supervisor: Suzanne Hodge

Email: s.hodge@lancaster.ac.uk

You have been invited to participate in a study exploring the experiences of people who have received a diagnosis of Autism Spectrum Condition after a previous diagnosis of a Personality Disorder during their time in secondary mental health services.

Before taking part in the study, please read the participant information sheet and add your initial to the boxes below if you are agreeable to each statement. Please speak to a member of the research team if you have any questions relating to the information on this form.

1. I confirm that I have read and understand the information sheet (version 1.1 19.09.2023) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily	
2. I understand that my participation is voluntary and that I am free to withdraw at any time during my participation in this study, without giving any reason; however, I understand that my data will only be removed if I withdraw within 2 weeks of taking part in the study. I understand that if I do not withdraw within two weeks, my data will still be used.	

3. I understand that any information given by me may be used in future reports, academic articles, publications or presentations by the researcher, but my personal information will not be included and all reasonable steps will be taken to protect the anonymity of the participants involved in this project.	
4. I understand that my name will not appear in any reports, articles, or presentations without my consent.	
5. I understand that any interviews will be audio-recorded and transcribed verbatim (word for word), and that data will be protected on encrypted devices and kept secure.	
6. I understand that the researcher will discuss research data with their research supervisor as needed.	
7. I consent to my anonymous interview transcripts being kept according to university guidelines for a minimum of 10 years after the end of the study.	
8. I agree to take part in the above study.	

______________________ ______________ _______________

Name of Participant Date Signature

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

Signature of Researcher /person taking the consent__________________________ Date ___________ Day/month/year

One copy of this form will be given to the participant and the original kept in the files of the researcher at Lancaster University

Appendix 7

Distress Protocol

Identifying distress

- The participant indicates they are experiencing emotional distress or exhibits behaviours that suggests they are distressed such as crying, shaking etc.

Stage 1 support

- The researcher will pause the interview and the participant will be informed that they are able to withdraw at any time.
- The researcher will offer the participant opportunity to take a break or move onto a different topic.
- The researcher will use any support techniques that the participant identified as helpful during the introduction to the interview.
- If the participant feels able to carry on the interview will resume.
- Direct the participant to the support resources listed in the participant information sheet.
- If the participant feels unable to carry on go to stage 2.

Stage 2 Support

- Ask the participant if they would like to stop the interview (if no, return to phase 1).
- If the participant agrees that they would like the interview to stop, ask the participant if they would like to withdraw from the study or continue the interview at another time.
- Direct the participant to the support resources listed in the participant information sheet or approach their mental health team for support if recruited by NHS staff.

Appendix 8

Poster for NHS Recruitment

Lancaster University

RESEARCH OPPORTUNITY

Have you received a diagnosis of Autism Spectrum Disorder in the last 5 years, having previously received a diagnosis of Personality Disorder?
Have you also accessed secondary mental health services?

I WANT TO HEAR FROM YOU!

My name is Jade Dalton, I am a Trainee Clinical Psychologist at Lancaster University, and I want to give you the opportunity to share your experiences of secondary mental health services as part of my research for training.

Participating in this research will involve completing a short screening questionnaire with a member of your care team, and then an hour long interview with me if you meet the inclusion criteria. Interviews can be held face to face or via MicrosoftTeams.

If you would like to take part, please ask a member of your care team to complete the short screening questionnaire with you. For further information please contact:
Jade Dalton - j.dalton6@lancaster.ac.uk

Appendix 9

Poster for Social Media Recruitment

Lancaster University

RESEARCH OPPORTUNITY

Have you received a diagnosis of Autism Spectrum Disorder in the last 5 years, having previously received a diagnosis of Personality Disorder?
Have you also accessed secondary mental health services?

I WANT TO HEAR FROM YOU!

My name is Jade Dalton, I am a Trainee Clinical Psychologist at Lancaster University, and I want to give you the opportunity to share your experiences of secondary mental health services as part of my research for training.

Participating in this research will involve completing a short screening questionnaire which you will send to me, and then an hour long interview with me if you meet the inclusion criteria. Interviews can be held face to face or via MicrosoftTeams.

If you would like to take part, please contact me on the email address below for further information and a copy of the screening questionnaire:
Jade Dalton - j.dalton6@lancaster.ac.uk