Investigating the Psychological Consequences of Adult-Onset Craniopharyngioma.

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Abstract

Background: The physical health impact of a diagnosis of Adult-Onset Craniopharyngioma (AOC) has been extensively explored and understood in the literature. However, a diagnosis of AOC also impacts the psychological well-being of patients, and there is a dearth of research that explores this.

Literature review: A literature review was conducted to explore the existing literature on the psychological well-being and quality of life of patients with AOC. This review revealed that patients do experience psychological difficulties, however, it highlighted a need for further research.

Aim and method: The studies aimed to quantitatively assess the impact of AOC on patients' mental health and psychological outcomes and to assess if a diagnosis of AOC impacts ratings of social and emotional content. Study One employed a survey-based design, and Study Two employed an experimental-based design. Participants with AOC were matched to controls for comparison. Thirty-six participants with AOC participated in Study One, and 19 completed Study Two.

Results: Study One results found that participants with AOC demonstrated significantly more depressive and anxious symptoms, greater alexithymia, and poorer social functioning. Participants with AOC also had greater disruption related to their body size, greater fatigue, and more life disruption due to vision impairment. Additionally, participants with AOC had significantly lower satisfaction with life and their depression, anxiety, resilience and fatigue scores significantly predicted their satisfaction with life. Study Two did not find a significant difference between ratings of social and emotional content between participant groups.

Conclusions: The findings of the present thesis revealed that participants with AOC experience psychological difficulties, with some areas of psychological functioning being worse than others. The studies offer new insights into the understanding of the psychological health of participants with AOC. The findings highlight important areas to be focused on in future practice, theory and research.

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Chapter One: Introduction

1.1 Chapter Summary

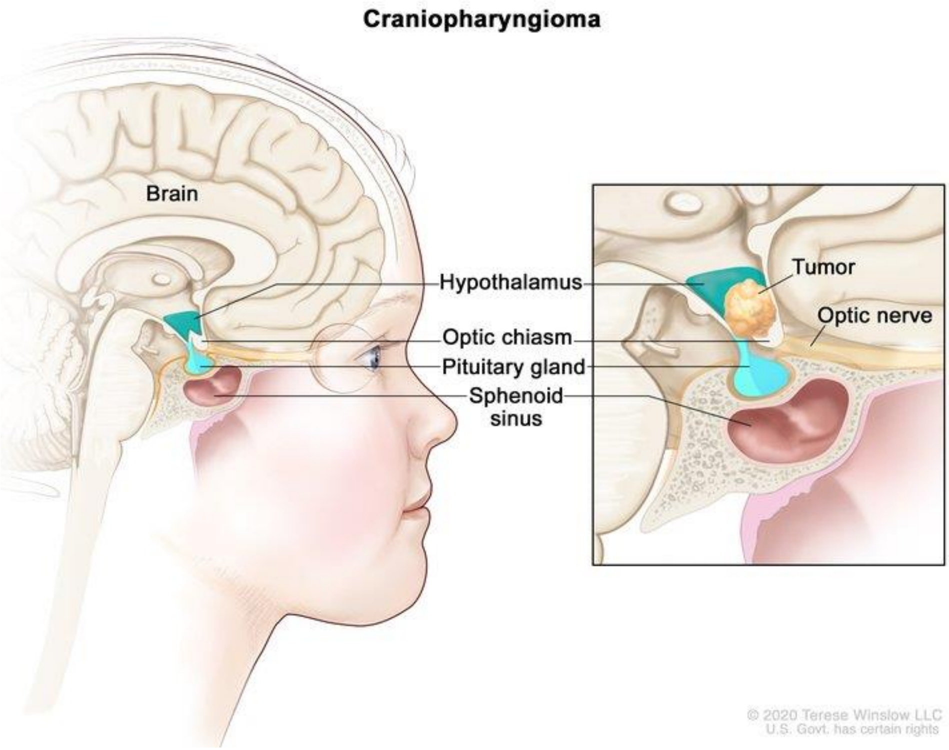
This chapter will provide the introductory context for the present thesis which aims to quantitatively explore the psychological impact of Adult-Onset Craniopharyngioma (AOC). It will begin with historical understandings and cover the clinical presentation, histological subtypes and theories of AOC. This will include the specifics on treatment options and prognosis, whilst also considering the impact on the oxytocin system. It will then go on to focus on the physical and psychological impacts of the diagnosis. The chapter will then present findings of a systematic literature review that explored the available research that investigated the impact that AOC has on a patient's psychological well-being and quality of life. Lastly, the rationale of the thesis will be explored.

1.2 Craniopharyngioma

Craniopharyngiomas are rare, slow-growing, and benign brain tumours commonly forming in the pituitary gland and hypothalamus. The tumour is located in the hypothalamo-pituitary area (Muller, 2014) (shown in Figure 1). These tumours are not considered to be malignant but can cause increased intracranial pressure, leading to visual impairment, problems with growth, and hypothalamic/pituitary deficiencies (Muller, 2014). The rare nature of craniopharyngioma leads to an incidence rate of 0.5 to 2 cases per one million of the population (Muller, 2014). Yet, when considering brain tumours of the sellar region, 88% of these are pituitary adenomas or craniopharyngiomas (Hamblin et al., 2022). Furthermore, craniopharyngiomas have a bimodal age distribution and incidence in male-to-female is equal (Momin et al., 2021).

Figure 1

A Common Location of a Craniopharyngioma



Note. Craniopharyngioma [Image], by Winslow, (2021), National Cancer Institute (https://visualsonline.cancer.gov/details.cfm?imageid=12622)

1.2.1 Historical Understandings of Craniopharyngioma

A description of craniopharyngioma was first shared in 1857 by Friedrich Albert von Zenker. He was a German pathologist, and his autopsy reported a cystic suprasellar mass with cholesterol crystals and squamous epithelium (Barkhoudarian & Laws, 2012). Following this, further findings were made which contributed to Mott and Barret's understanding of the craniopharyngioma pathogenesis, which they shared in 1899 (Mott & Barret, 1899). Shortly thereafter Jakob Erdheim accurately described the histopathological characteristics of craniopharyngioma in 1904, the tumours were referred to as "Erdheim tumours" (Erdheim, 1904).

In 1893 the first clinical manifestation was described by Rupert Boyce and Cecil Beadles, referring to a 35-year-old patient (Boyce, 1893) and then in 1909 the first successful surgical resection took place in Chicago (Halstead, 1910). By 1930 there were many more terminologies referring to craniopharyngioma, and in 1931 the modern term “craniopharyngioma” was invented and within a year further popularised due to Harvey Cushing’s report on brain tumours (Barkhoudarian & Laws, 2012).

Mortality from surgery was high and advances in healthcare improved this, namely the advances in electrosurgery, antibiotics and corticosteroids (Cushing, 1928). Surgical morbidity and mortality continued to improve due to an improved understanding of postoperative complications and the development of computed tomography (CT) imaging (Barkhoudarian & Laws, 2012). Magnetic resonance imaging (MRI) was then introduced and proved to be superior to CT, improving the management of craniopharyngioma (DiPatri & Prabhu, 2005). The use of MRI offered comprehensive information regarding the location of the tumour to nearby structures (Raimondi & Rougerie, 1994). The subsequent improvement in surgical technique and advances in management options led to better outcomes, with improvement in treatment outcomes with regard to morbidity and mortality of patients (DiPatri & Prabhu, 2005). The treatment approach to craniopharyngioma is discussed in detail in section 1.2.6.

1.2.2 Clinical Presentation

Childhood-Onset Craniopharyngioma (COC) represents between 30 and 50% of cases of craniopharyngioma (Jensterle et al., 2019). Palmisciano et al (2022) report that in children, peak incidence rates are between five to 14 years. A similar peak incidence of five to 15 years is reported by Muller et al (2020). In children, a diagnosis of craniopharyngioma constitutes around 6-9% of intracranial tumours (Stripp et al., 2004). Palmisciano et al (2022) report that in adults, peak incidence rates are between 50 to 74 years. The same peak incidence age was reported by Muller et al (2020).

Due to the location of the tumour, commonly situated near the pituitary gland and hypothalamus, the craniopharyngioma tumour can cause various symptoms. Some of the common causes of symptoms and signs that patients present with are thought to be compression of the pituitary stalk/gland, pressure on the optic nerves and hypothalamic involvement (Zoicas & Schöfl, 2012). The consequences of disruption to these vital areas of the brain lead to the clinical manifestation of craniopharyngioma. This has been understood to commonly be headaches, visual disturbances and endocrine deficiencies (Cuny et al., 2025). Mushtaq et al (2024) found that in 75% of COC cases, headaches were the most common physical symptom. Other physical symptoms reported include nausea and vomiting, of which 50% of patients reported this symptom. Cuny et al (2025) reported that symptoms are often related to intracranial hypertension, headaches and visual disturbances. Furthermore, craniopharyngioma may be suggested if a child patient has stunted growth and weight gain.

In adult-onset cases, 55% reported deterioration in vision; 45% reported headaches and 27% reported nausea and vomiting (Mushtaq et al., 2024). Also, it has been understood that the majority of adult patients initially presented with signs of hypopituitarism and visual field deficits (Hoff & Patterson, 1972). Furthermore, in adult-onset cases, 17% of patients reported failure to thrive and hypogonadism was a manifestation commonly reported (Mushtaq et al., 2024).

1.2.3 Diagnosis

Diagnosis of craniopharyngioma can be made late, and the initial symptoms patients present with are often unspecific (Jensterle et al., 2019). The duration of symptoms before diagnosis of COC ranges from one week to 10 months, and AOC ranges from one week to 36 months (Mushtaq et al., 2024). Prior to diagnosis, various investigations are conducted, including biochemical and hormonal analysis, imaging and visual assessments (Cuny et al., 2025). As mentioned earlier in this chapter, in the present day, the use of CT and MRI to scan the brain and skull base is important for the diagnosis of craniopharyngioma (Mushtaq et al., 2024). With the use of CT, the calcifications of the tumour and bony structures are best assessed, whilst the use of MRI allows the involvement of adjacent structures to be evaluated together with the tumour size (Zoicas & Schöfl, 2012).

Research has found that the average tumour size in a sample of patients less than 20 years old was 25.8cm^3 and 17.9cm^3 in those over 20 years old (Eldevik et al., 1996). Furthermore, cyst size and calcification size were larger in those under 20 years old compared with those over. However, this difference was not statistically significant.

1.2.4 The Two Main Histological Subtypes

Craniopharyngiomas are classified as WHO grade 1 tumours (Louis et al., 2021) and are found along the craniopharyngeal canal, commonly arising in the sellar and parasellar region of the brain (Mushtaq et al., 2024). The previous two main histological subtypes of craniopharyngioma are now classified as distinct tumour types (Louis et al., 2021). The adamantinomatous tumour type has been described as cyst formation with calcifications, but can also have solid components or be mixed solid and cystic, most common in children. Whilst the papillary tumour type, most commonly found in adults, is usually solid or mixed cystic and solid (Eldevik et al, 1996). Both tumour types can have a poor prognosis. In COC, the pathohistological type is 99% adamantinomatous with papillary being exceptionally rare (Jensterle et al., 2019). Mende et al (2020) found that in AOC, over 60% of cases were classified as adamantinomatous and just over 10% of cases were papillary. In some cases, it was not possible to make a detailed classification of the tumour.

1.2.5 Theories

While no single theory can comprehensively cover all aspects of craniopharyngioma, considering a variety of different theories can provide a better understanding of the impact of the disease. These theories can help to consider the wide range of challenges faced by those with craniopharyngioma. The application of theories to craniopharyngioma may provide guidance on the type of psychological support that would be beneficial for these patients.

1.2.5.1 Psychosocial models of chronic illness. Craniopharyngioma has been described as a chronic disease (Jensterle et al., 2019; Müller, 2015) and can be understood with reference to the Chronic Illness Trajectory Model (CITM). This is a framework that was designed to help understand the experience of individuals living with chronic illness (Corbin & Strauss, 1991). The CITM outlines the development and progression of chronic illness, with an understanding of the various phases an individual will go through. There is a constant and dynamic process for individuals as they cope, adjust and manage over time. This process for individuals is experienced uniquely. However, common phases can be seen when considering changes in health status and the need for intervention (Burton, 2000). An important area that the CITM highlights is the relationship between the illness and the patient's emotional and social experiences. The nature of craniopharyngioma means that often long-term intervention or follow-up is required, making the CITM useful in mapping how patients navigate through their lives.

Before an individual is diagnosed with craniopharyngioma, they may experience symptoms for a period of time (weeks to months), which can be understood by the CITM as the 'pre-trajectory phase' (Corbin & Strauss, 1991). During this phase, the individual may be unsure what is wrong, and they may seek medical opinions. This phase may have a pronounced psychological impact due to uncertainty and fear. Once an individual is diagnosed with craniopharyngioma, they can then be understood to be in the phase of ‘trajectory onset’. During this phase, patients may commonly be shocked and need a period of adjustment. At this phase, medical intervention may begin, with craniopharyngioma this may be surgery or radiation therapy. The acute management of the tumour is important, whilst this may be accompanied by post-surgical complications and difficulties. The medical intervention and outcome will impact the patient’s trajectory. A period of stability follows, known as the ‘stable phase’ (Corbin, 1998). Patients with craniopharyngioma may still need to manage their ongoing health concerns with regular follow-up appointments and lifelong hormone replacement medications. This long-term management of craniopharyngioma is accompanied by emotional adjustments and psychological challenges. During the stable phases, patients may worry about tumour recurrence and frustrations with post-intervention symptoms that are difficult to manage.

Subsequently, patients with craniopharyngioma may enter the ‘unstable phases’, within this phase, they experience recurrence or complication (Shi & Geng, 2024). A recurrence of the tumour may lead to further surgery or radiation and the potential worsening of previously well-managed symptoms. Feelings of uncertainty may be experienced by the patient at this time and a lack of control may be felt. Many craniopharyngioma patients are successfully treated. However, some patients may experience a downward phase, signified by a decline in health and well-being. The tumour may have led to the development of other chronic conditions; therefore, the patient will be managing multiple chronic conditions. Lastly, death may occur, whilst craniopharyngioma is benign and treatable, there can be complications in rare cases.

The CITM’s application to craniopharyngioma can help to draw attention to the complex and evolving nature of living with this disease. This understanding emphasises the need for holistic care and can help professionals optimally support patients navigating diagnosis and managing the chronic condition.

1.2.5.2 Biopsychosocial Model. A perspective that is useful when considering physical health and disease is the Biopsychosocial Model, first proposed by George Engel (Engel, 1977). This viewpoint attempts to integrate the biological, psychological and social processes whilst also considering how they interact (Suls & Rothman, 2004). Specifically, when considering craniopharyngioma, the Biopsychosocial Model can be relevant as the tumour's biological effects may contribute both directly and indirectly to psychological issues and, in turn, may therefore have an impact on a patient's social life. A crucial part of this model is that physical health and well-being are formed at the interface of biological, psychological and social factors (Suls & Rothman, 2004).

As mentioned earlier in this chapter, craniopharyngiomas are located near critical brain structures, including the hypothalamus and pituitary gland. The location of the tumour impacts a range of biological functions, it directly inhibits the function of the hypothalamus and pituitary gland (Zoicas & Schöfl, 2012). The implications of this include dysregulated appetite signals, sleep regulation difficulties and hormonal imbalances in relation to sex hormones, cortisol and oxytocin (Apps et al., 2023). As a result of these biological impacts, one can anticipate psychological consequences.

There are many reasons why a craniopharyngioma may have an impact on the psychological functioning of an individual. Commonly, a craniopharyngioma will require some form of treatment, and the individual will have to cope with a wide range of symptoms that present prior to treatment and post-treatment. And, as previously discussed, there is also an emotional and cognitive impact of living with a chronic condition.

When considering the impact that craniopharyngioma has on biological and psychological factors, it is understandable that there would be an impact on the social aspects of an individual's life. The building and maintenance of relationships may prove difficult with craniopharyngioma, and an individual's quality of life may be impacted. Making these links between biological, psychological and social variables is important, and consequently, patients require a wide range of diverse professional disciplines via a multidisciplinary team to understand these links and their impact on the patient (Suls & Rothman, 2004). Both medical and allied health professionals work collaboratively in a multidisciplinary team to consider options for intervention and to develop a person-centred care plan (Ke et al., 2012).

1.2.6 Treatment of Craniopharyngioma

The modern goal of treatment has been described as “maximal hypothalamic-sparing resection” by Cossu et al (2020). It is important to note that this has not always been the case; surgical resection previously focused on maximum removal of the tumour, which understandably has impacts on the patient. The evolution of the treatment of craniopharyngioma has been important for improvement in outcomes and quality of life.

The first-line approach for treating craniopharyngioma is surgical resection (Zoicas & Schöfl, 2012) and the benefits are considered alongside the risks of treatment-related morbidity. The current three surgical approaches are transcranial (accessing the brain through an opening in the skull), transsphenoidal (intervention through the nose and sphenoid sinus) or supraorbital (intervention through an eyebrow incision) (Webb et al., 2023). Following surgery, radiotherapy may be offered, and retrospective studies have reported 75-90% 10-year tumour control rates following radiotherapy, whereas incomplete excision alone found 30-50% control rates (Aggarwal et al., 2013). However, patients commonly experience long-term consequences following treatment that negatively affect their quality of life (Muller et al., 2020).

Webb et al (2023) concluded that improved clinical outcomes are found when a transsphenoidal approach is used when resecting craniopharyngioma. Despite this, it is important to acknowledge that research has found that post-operative complications can occur when resecting craniopharyngioma, some reported complications include electrolyte imbalance, visual deterioration and haemorrhage (Mende et al., 2020). Recently Henderson & Schwartz (2022) concluded that the goal of surgery is to ensure safe resection to accomplish a cure, and if this is not possible then subtotal resection alongside radiation may be similarly effective. Stripp et al (2004) found no significant difference between the overall survival of children and young adults that had gross total or subtotal resection, followed by postoperative radiotherapy.

As previously stated, when gross total resection of the craniopharyngioma is not possible, it is recommended that radiotherapy is administered (Karavitaki, 2014). Radiotherapy can be useful to prevent the need for multiple surgeries, as this is associated with morbidity and mortality. Additionally, radiotherapy improves recurrence-free survival rates by 75-90% (Scaringi et al., 2018). Occasionally radiotherapy treatment can be recommended without surgery (Hill et al., 2019), and recent advances in treatment precision have improved, and long-term toxicity has been reduced (Zoicas & Schöfl, 2012). Depending on the treatment a patient with a diagnosis of AOC undergoes, this will have a direct impact on outcomes and quality of life.

1.2.7 Prognosis

Craniopharyngioma survival at five years follow-up is 90%, reducing to 77% at 20 years follow-up (Wijnen et al., 2017). The overall mortality of those with craniopharyngioma tends to be three to five times higher than that of the general population (Sherlock et al., 2010). The long-term prognosis of patients with craniopharyngioma is impacted by the recurrence of the tumour (Zoicas & Schöfl, 2012), and research has concluded that the first recurrences occur in a median timeframe of 2.5 years (Karavitaki et al., 2005).

1.2.8 The Oxytocin System

The peptide hormone, oxytocin, has demonstrated a significant role in a range of behaviours. Most importantly, human social and emotional behaviours are affected by oxytocin, such as response to social exclusion (Riem et al., 2013) finding that oxytocin has a positive effect on prosocial behaviour. Oxytocin is important in regulating the processing of emotional information (Hubble et al., 2017). The location of the craniopharyngioma tumour leads to disruption of the pituitary gland functioning (Apps et al., 2023) Due to oxytocin's production in the posterior pituitary gland, the production of oxytocin is disrupted and reduced by a craniopharyngioma tumour (Daughters et al., 2017). This direct biological functioning disruption, leading to oxytocin deficiency in patients with AOC, could lead to psychological functioning consequences. Therefore, the consideration of the hormone oxytocin is important when working with patients with COC and AOC, in relation to their social and emotional responses.

Notably, oxytocin is now well recognised with regard to the role it plays in social bonds (Carter et al., 2009). This research suggests that patients with craniopharyngioma, who experience oxytocin deficits, may also experience a significant impact on their social functioning (Daughters et al., 2017). The behavioural and physiological functions of oxytocin have helped in the development of complex social interactions and social bonds (Carter, 2014). Moreover, oxytocin has been connected with social attention (Guastella & Macleod, 2012), essential for social communication and interaction. Oxytocin has been found to promote emotional states that allow optimum development and the social use of others during periods of stress and restoration (Carter, 2014). It should be noted that the importance of oxytocin is not limited to humans, oxytocin is found in all mammalian species and oxytocin-like-molecules can be found in a wide range of species, and research demonstrates that they have a similar function to humans, regulating important social behaviours (Garrison et al., 2012; Triki et al., 2022).

Previous research has suggested that the proposed contributors to the morbidity of craniopharyngioma include oxytocin deficiency (Castle-Kirszbaum et al., 2022; Daughters et al., 2017). As oxytocin is produced in the hypothalamus and secreted by the posterior pituitary gland (Daubenbüchel et al., 2016), and craniopharyngiomas develop near the pituitary gland and hypothalamus along the glandular tissue of the pars tuberalis covering the pituitary stalk (Diaz et al., 2022) it is important to consider the impact that craniopharyngiomas will have on the production and secretion of oxytocin. It is well-documented that a common complication of craniopharyngioma is hypopituitarism (Castle-Kirszbaum et al., 2022). It has been found that approximately half of all patients with COC or AOC present with one or more endocrine deficits at the time of diagnosis (Caldarelli et al., 2005). However, it is less known/documented that this includes an oxytocin deficiency and its potential impacts on patients' psychological functioning.

A systematic review was conducted that aimed to assess the degree to which the oxytocin system is involved in craniopharyngioma and the impact that it has on abnormalities in neurobehaviour and metabolism (Mann et al., 2024). The dysfunction of the oxytocin system is not well understood within the craniopharyngioma population. The review identified limited studies in this area making it difficult to draw definitive conclusions, however, the review concluded that the oxytocin system may be compromised in individuals with craniopharyngioma. Furthermore, research has found an inability to release additional oxytocin in response to stimulation from physical exercise or social stress (Valstad et al., 2017). Hormonal deficits must be considered due to tumour resection not reversing hormonal deficits (Karavitaki et al., 2005) and long-term pituitary hormone deficiencies being found in 98% of craniopharyngioma patients (Wijnen et al., 2017). The oxytocin response deficit which is present in those with craniopharyngioma has led to the expectation of differing social cognitions in those with craniopharyngioma than controls (Daughters et al., 2017; Gebert et al., 2018). This assumption – that those patients with AOC present with an oxytocin deficit – forms the theoretical underpinnings for the current thesis.

1.2.9 The Physical Health Impact

Long-term physical health conditions are observed in both COC and AOC, notably pituitary hormone deficiencies, visual disturbances and obesity (Apps et al., 2023). Following treatment for AOC, patients often experience significant weight gain and an increased prevalence of obesity, leading to the predisposition of increased risk of metabolic complications (Dogra et al., 2022). Endocrine consequences for patients are common, with children presenting with hormone deficiencies between 40-87% of the time and adults around 73% of the time (Jensterle et al., 2019). Visual impairment has been commonly reported, and fortunately, post-surgical improvement is noted in some cases (Frio et al., 2019; Koutourousiou et al., 2013; Patel et al., 2015). As expected, much of the literature on AOC to date focuses on the physical health impact, with little focus on the psychological health impact, however, as just described there is a strong rationale to expect both a direct and indirect impact of AOC on a patient's psychological wellbeing.

1.2.10 The Psychological Health Impact

The existing research heavily focuses on the physical health implications of craniopharyngioma, and often, consideration of the psychological impact of the tumour is not the primary focus of research. The limited research investigating the psychological impact has been carried out by medical professionals. For example, patients with COC were found to have significantly more psychiatric conditions compared with patients with AOC, however, the prevalence in AOC was still notable (Wijnen et al., 2017).

The impact that craniopharyngiomas have on quality of life has been explored in a recent systematic review of 25 studies, including a total of 2025 patients from the adult and paediatric population. The review found across studies that patients with craniopharyngioma had lower quality of life than the general population. Notably, common complaints after surgery include social and emotional dysregulation (Castle-Kirszbaum et al., 2022). The association of AOC with a complex sociological and psychological burden and hypothalamic dysfunction is evident and further treatment methods are necessary (Mende et al., 2020). Whilst Castle-Kirszbaum et al (2022) carried out a comprehensive systematic review of the literature, this review noted that the studies reviewed were at high risk of bias, with small sample sizes, and retrospective accounts of patient quality of life. There was also a high number of cohort studies included in the review. Therefore, it is necessary to conduct further research with the use of psychological measures and tasks which are well suited to build an understanding of the complex social behaviours that appear to be impacted by AOC. The area of expertise of the researchers will be utilised to investigate areas of interest that have not currently been met with the highly medically-focused literature.

Craniopharyngioma resection is often associated with neuropsychological deficits, which, in turn, impairs quality of life (Giese et al., 2019). This review used the 36-Item Short Form Survey (SF-36) to gather data about quality of life. Whilst it was determined that quality of life was impaired in at least one dimension in 75% of the patient sample, this questionnaire was designed as a generic health measure, meaning it may have a limited ability to capture complex social phenomena. The SF-36 was also used in other adult studies on Quality of Life (Dekkers et al., 2006; Pickering et al., 2014; Roemmler-Zehrer et al., 2015). The unfavourable prognosis of craniopharyngioma is well-known, however, it is not well understood, and data on long-term consequences is limited. Research has been conducted to recognise indicators of recurrence and factors connected to differing quality of life and compromised social rehabilitation in those patients with both COC and AOC (Gautier et al., 2012). This study utilised the WHO-QOL BREF measure, another measure of quality of life (World Health Organization, 2004). Although there has been support for this measure (Vahedi, 2010), it is also recognised that it could be further improved. Therefore, it is important future research not only includes generic health measures but also more specific measures that are designed to capture nuanced areas of quality of life, and physical and mental health. The present thesis will utilise gold-standard psychological measures to thoroughly investigate the psychological impact of craniopharyngioma, thereby adding the necessary balance to the current medical findings.

The recent review (Castle-Kirszbaum et al., 2022) of the quality of life in craniopharyngioma demonstrated, as expected, that patients with craniopharyngioma suffer a worse quality of life than that of the general population. It was also found that most existing studies were small, retrospective, cohort studies with a high risk of bias. Importantly for this thesis, the review found that quality of life in the paediatric cohort had been more extensively investigated than in adult patients, providing further emphasis on the need to study AOC. The noteworthy differences between COC and AOC mean that not all findings within paediatric cohorts can be generalised to adult cohorts. It is also noted that to optimally manage the complex cases of all craniopharyngioma patients an experienced multidisciplinary team is required. Therefore, the present thesis will aim to contribute towards how teams can best manage the consequences of the tumour taking into account the many different professionals that can offer their expertise.

This recent review has highlighted the importance of future studies having larger sample sizes and minimising the risk of bias which the present thesis aims to do. Furthermore, an important aspect of future studies is to ensure the use of psychological measures and tasks as these are better suited to understanding the complex social and emotional behaviours that appear to be affected by COC and AOC. The present thesis will explore many aspects of functioning that are not currently being met by the existing medically-focused literature.

Finally, in an attempt to offset the medical questionnaire-based literature to date, qualitative psychological research methods have been utilised to offer new insight into the psychological impact of AOC. A recent study carried out by Daughters et al (2023) identified that patients would benefit from hearing about other patients' experiences of being diagnosed and living with AOC. This may provide a sense of reassurance and the lack of psychological focus in research suggests further exploration is needed to support and reassure patients. Relatedly, other research has demonstrated that when physically unwell a patient may experience many physical losses (Moos & Tsu, 1977), however, the patient may also struggle with feelings of loss concerning changes in career prospects, family roles, or life goals due to the physical and cognitive effects of the tumour and its treatment.

Notably existing literature has had a limited focus on these psychological impacts, it is important to systematically review this literature to gain a thorough understanding of the knowledge gained. The below systemic review will aim to do this, consequently leading to a robust rationale for the present thesis.

1.3 Systematic Literature Review

1.3.1 Introduction

A systematic literature review was conducted to identify the existing literature that draws attention and understanding to the psychological well-being and quality of life of AOC patients. Identifying the research allows the opportunity to appraise and synthesise important findings (Munn et al., 2018). Given the research presented above, particularly that it predominantly focuses on the physical health consequences of the diagnosis and treatment of craniopharyngioma, it felt important to ensure all research was taken into consideration, primarily focusing on the research that has been conducted to explore the other impacts of craniopharyngioma.

Previously, a systematic review exploring the quality of life in craniopharyngioma patients was conducted (Castle-Kirszbaum et al., 2022). This review looked at both paediatric and adult populations. The present review aimed to build on the findings of this previous review, focusing solely on the adult population, whilst additionally reporting on any psychological impact. Therefore, this section of the chapter provides a description of the systematic literature review that was conducted to consider whether a diagnosis of AOC impacts an individual's psychological wellbeing and quality of life. At the time of writing, no systematic literature review has been conducted to explore this. The research question was:

1. Does a diagnosis of AOC impact an individual's psychological wellbeing and/or quality of life?

1.3.2 Method

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Page et al., 2021) were used to conduct this review. The International Prospective Register of Systematic Reviews (PROSPERO) was searched to ensure the present research question had not been addressed in previous reviews.

1.3.2.1 Search Strategy. Three electronic databases were searched in December 2024: MEDLINE Ultimate, CINAHL Ultimate and APA PsycInfo. Any record from inception until December 2024 was considered for inclusion. The search terms were chosen to ensure all relevant records were included at this stage (Table 1). Results were filtered for terms in the abstract and full text using the advanced search feature on EBSCO (Essentials). For search term one the abstract filter was chosen due to literature commonly stating within the title or abstract whether the research looked at the paediatric or adult population. Additionally, search term two was filtered for full text due to psychological measures and quality of life are rarely being the sole focus of research in this field, therefore ensuring all potential records were found.

Table 1

Electronic Database Search Terms

Search number	Search terms	Field	Results generated
S1	Adult craniopharyngioma	Abstract	194
S2	Psychological OR Social OR Cognitive OR Distress OR Quality of life OR Well-being	All text	18,457,918
S3	S1 AND S2	As above	94

Searches for grey literature were carried out. MedNar, ProQuest Dissertations and Theses Global, Open Access Theses and Dissertations and Clinicaltrials.gov found no relevant records to consider for inclusion. Hand-searching of the reference lists of the 13 papers included in the present review were carried out, and citation searching was also conducted. No authors were contacted for purposes of this review.

In the present review, records were included if (a) participants were humans with AOC (b) the research reported on the psychological impact or impact on quality of life of an AOC diagnosis, even if this was not the main aim (c) qualitative or quantitative methodology (d) peer-reviewed records. Records were excluded if (a) the research did not report on the psychological impact or impact on quality of life of an AOC diagnosis (b) participants were humans with COC (c) records that had been included in the previous systematic review on quality of life (Castle-Kirszbaum et al., 2022) (Table 2) (d) single case study (e) review protocol or review (f) unable to stratify the data by age of onset (g) not in the English language.

Table 2

Summary of the Literature Excluded due to Being Included in the Systemic Review Conducted by Castle-Kirszbaum et al (2022)

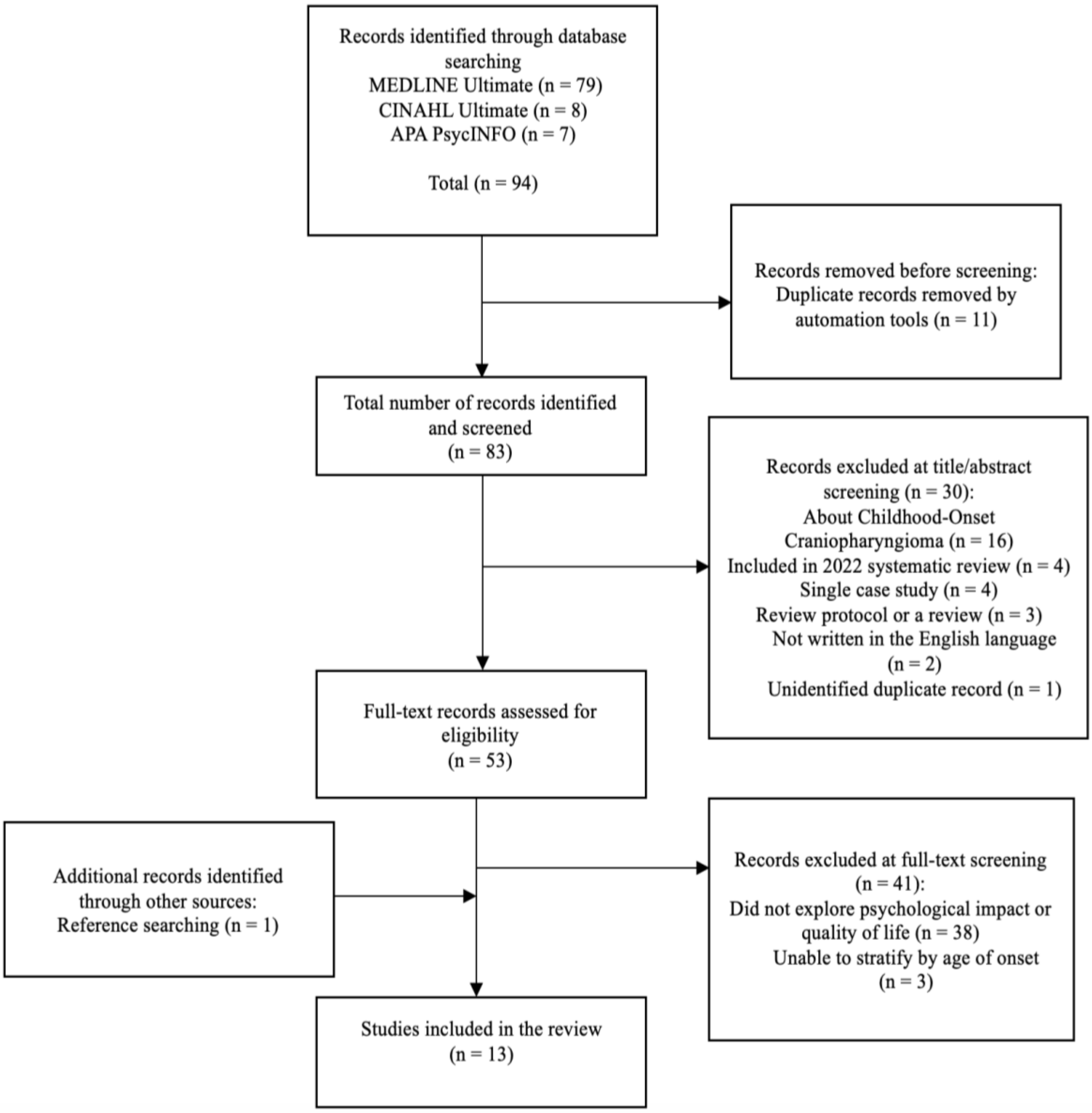
Author	Country	Sample size	Gender	Mean age at diagnosis (Minimum – Maximum)	Research design	SM or PRO	Pre- or post-operative report	Outcomes	Journal
Dekkers et al (2006)	Netherlands	29	48.28% female***	47.9 (11 – 80)***	Prospective	SM: NHP and SF-36	Post	Participants with AOC show continued impairment in quality of life.	European Journal of Endocrinology
Gautier et al (2012)	France	106	-	38 (28 – 52)*	Retrospective	SM: WHOQOL-BREF	Post	Participants with AOC scored lower than the general population.	Journal of Clinical Endocrinology and Metabolism
Giese et al (2019)	Germany	36	47.2% female	-	Prospective cohort	SM: SF-36	Post	Quality of life was impaired in at least 1 dimension of the SF-36 in 75% of the participants with AOC.	Journal of Neurosurgery
Honegger et al (1998)	Germany	13	69.2% female	45 (17 – 76)**	Prospective	SM: NHP	Pre and Post	Quality of life was normal before and after surgery.	Surgical Neurology

Note. *at presentation median (1st to 3rd quartiles); **at time of study; ***of the total sample that included COC; SM, Standardised Measure; WHOQOL-BREF, The World Health Organisation Quality of Life Brief Version; SF-36, The 36-Item Short Form Health Survey; NHP, Nottingham Health Profile

1.3.2.3 Screening Procedure. The complete screening process can be seen in the PRISMA diagram (Page et al., 2021) in Figure 2. Ninety-four records were produced when carrying out the electronic database search. The search results were recorded in an Excel Spreadsheet. Eleven records were excluded due to being duplicate records. Screening was carried out independently by the researcher with reference to the inclusion and exclusion criteria. Title and abstract screening were conducted, leading to the exclusion of 30 studies for six different reasons which are detailed in Figure 2. A full-text review was carried out for 53 remaining articles, resulting in the exclusion of 41 records for two reasons detailed in Figure 2. Twelve records were found to be suitable to include in the review. One further record was identified through reference searching, this record was screened and included in the review. No further relevant articles were found through citation or grey literature searching. In total, there were 13 records deemed suitable for inclusion in the review.

Figure 2

PRISMA Diagram of Search Procedure and Outcome



1.3.2.4 Quality Assessment. The individual methodological quality and risk of bias were assessed based on the “Mixed Methods Appraisal Tool version 2018” (MMAT), developed by Hong et al (2018). This critical appraisal tool was chosen as the present review includes both quantitative and qualitative studies. Although this tool advises two reviewers to be independently involved in the appraisal process, this was not possible due to the nature of the thesis. Segregation of studies occurred according to the study design category. Category options included qualitative, quantitative (randomised controlled trials; non-randomised;

descriptive) and mixed methods. Once the appropriate category was selected, appraisal occurred by rating the five criteria in the appropriate category, selecting either yes, no or can't tell. The researcher appraised based on the systematic review question, exclusively responding to the systematic review focus. An overall score was not calculated as this is discouraged by Hong et al (2018), therefore a detailed presentation of the ratings was generated.

1.3.2.5 Data Extraction and Synthesis. Data from the included studies was independently extracted by the researcher and categorised. The studies included gathered data regarding the psychological impact and quality of life in a variety of ways, therefore, due to observed heterogeneity in the data of included studies, a meta-analysis was not conducted. This review draws on a method of textual narrative synthesis (Lucas et al., 2007) to discuss the heterogeneous range of both quantitative and qualitative data. Firstly, several sub-groups were defined, followed by synthesis of data by taking into consideration the scope of findings, strengths and weaknesses. This approach felt most appropriate as it is thought a textual narrative synthesis (Lucas et al., 2007) is well-suited to reviews that aim to determine the scope of what has already been studied and the gaps that future research should address, such as this present review aims to do. However, it was not always possible to conclude across the included studies due to the lack of data and study heterogeneity.

1.3.3 Results

The chosen search terms identified 13 studies that met the criteria for inclusion. The study characteristics of these studies can be seen in Table 3. Of the 13 studies included in this review, 12 used quantitative methods (Apra et al., 2019; Dogra et al., 2022; Frio et al., 2019; Koutourousio et al., 2013; Lucia et al., 2024; Lucia et al., 2021; Mende et al., 2020; Patel et al., 2015; Rutenberg et al., 2022; Rutenberg et al., 2020; Wijnen et al., 2017; Zhao et al., 2021) and one study employed qualitative methods (Daughters et al., 2023). The total number of participants across studies was 691. The minimum age of participants was 18, and the maximum was 85. However, two studies (Dogra et al., 2022; Zhao et al., 2021) did not report this information. The studies saw data collected across six different countries: USA (n = 5), Germany (n = 3), France (n = 2), UK (n = 1), Netherlands (n = 1) and China (n = 1). The 13 studies were published between 2013 and 2024.

Table 3

Study Characteristics

Author	Country	Sample size	Gender	Mean age at diagnosis (Minimum – Maximum)	Research design	SM or PRO	Pre- or post-operative report	Outcomes	Journal
Apra et al. (2019)	France	22	70% female	58 (18 – 79)	Retrospective cohort	PRO	Pre Post	Reported on pre- and post-operative cognitive impairment. Included depression, psychiatric traits, pseudo dementia and employment status.	World Neurosurgery
Daughters et al. (2023)	UK	8 patients 10 clinicians	62.5% female 40% female	Patients 53 (31 – 72) * Clinicians 49 (37 – 74)	Qualitative, semi-structured interviews	PRO	Pre Post	Identified two core themes: patients experience psychological impacts of AOC and patients also experience common physical symptoms. Within these core themes, subthemes were identified.	European Journal of Oncology Nursing
Dogra et al. (2022)	USA	91	44% female	48	Retrospective cohort	PRO	Pre	Reported mental status at presentation.	Endocrine
Frio et al. (2019)	France	11	27.3% female	50 (18 – 77)	Retrospective cohort	PRO	Pre Post	Reported cognitive and behaviour disorders at presentation and post-operative.	World Neurosurgery
Koutourousiou et al. (2013)	USA	47	Male: female ratio 1.5:1	51 (28 – 82)	Retrospective cohort	PRO	Pre	Reported mental changes at presentation.	Journal of Neurosurgery

Author	Country	Sample size	Gender	Mean age at diagnosis (Minimum – Maximum)	Research design	SM or PRO	Pre- or post-operative report	Outcomes	Journal
Lucia et al. (2024)	Germany	12	33.3% female	43 (23 – 73)	Retrospective and prospective cohort	SM: NCCN-DT	Pre Post	Reported psychosocial stressors pre- and post-operatively. Also reported psychosocial stressors with the NCCN-DT measure.	World Neurosurgery
Lucia et al. (2021)	Germany	20	-	46.2 (21 – 68)	Retrospective cohort	PRO SM: EORTC, QLQ-C30	Pre Post	Reported post-operative return to work and independence. Also reported on quality of life utilising the EORTC QLQ-C30.	World Neurosurgery
Mende et al. (2020)	Germany	148	50% female	46 (18 – 81)	Prospective and retrospective cohort	PRO SM: EORTC QLQ C30 and BN20	Pre Post	Reported the pre- and post-operative presence of eating disorders. Also reported on quality of life utilising the EORTC QLQ-C30 and BN20.	The Journal of Clinical Endocrinology & Metabolism
Patel et al. (2015)	USA	31	61.3% female	49.3 (20 – 85) **	Prospective cohort	SM: ASBQ, SNOT-22	Pre Post	Reported on quality of life with the Wen Class, ASBQ and SNOT-22.	Journal of Neurosurgery
Rutenberg et al. (2022)	USA	49	49% female	45 (17 – 72)	Retrospective cohort	PRO	Pre	Reported cognitive, memory and personality changes reported at presentation.	Journal of Neuro-Oncology

Author	Country	Sample size	Gender	Mean age at diagnosis (Minimum – Maximum)	Research design	SM or PRO	Pre- or post-operative report	Outcomes	Journal
Rutenberg et al. (2020)	USA	14	64.3% female	26 (19 – 53)	Retrospective cohort	PRO	Pre	Reported cognitive, memory, personality and behaviour changes reported at presentation.	Journal of Neuro-Oncology
Wijnen et al. (2017)	Netherlan-ds	65	51% female	41 (29 – 55)	Cross sectional study based on retrospective data	PRO	Pre Post	Reported neurological deficits, cognitive impairment and behavioural changes pre- and post-operative. Also reported long-term outcome of psychiatric conditions.	European Journal of Endocrinology
Zhao et al. (2021)	China	173	49.1% female	42.03	Retrospective case-control	SM: NPI-Q	Post	Reported psychiatric disorders after surgery with the NPI-Q.	Frontiers in Neurology

Note. *at time of the study; **at time of surgery; SM, Standardised Measure; PRO, Patient-Reported Outcomes; NCCN-DT, National Comprehensive Cancer Network Distress Thermometer; EORTC QLQ-C30, 30-item core European Organisation for Research and Treatment of Cancer Quality of Life questionnaire; EORTC QLQ-BN20, 20 item European Organisation for Research and Treatment of Cancer Quality of Life questionnaire Brain Tumour Module; ASBQ, Anterior Skull Base Quality of Life questionnaire; SNOT-22, 22-item Sinonasal Outcome Test; NPI-Q, Neuropsychiatric Inventory Questionnaire

1.3.3.1 Assessment of Study Quality. Hong et al (2018) discourage the exclusion of studies with low methodological quality, therefore no study was excluded following the assessment of quality and this information can be used to contribute to the strength of evidence. There was variation in the quality of the studies included in the review as can be seen in Table 4 and Table 5. These tables show the results of the assessment of study quality, the appraisal is based on the present systematic review focus.[1] The qualitative study had the highest quality, whereas the quantitative studies varied in their quality. For the quantitative studies, the majority of participants may not be representative of the wider population as they were from only one or two medical centres. Another shortcoming of the quantitative studies was that not all participants contributed to all measures. The quantitative studies accounted for confounders well and the exposure occurred as intended.

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[1] If the assessment of study quality included appraisal of the physical health factors, this would lead to limited conclusions for the existing literature that the present systematic review is interested in.

Table 4

MMAT Non-Randomised Quality Appraisal Tool

	Methodological quality criteria				
Author	Are the participants representative of the target population?	Are measurements appropriate regarding both the outcome and intervention (or exposure)?	Are there complete outcome data?	Are the confounders accounted for in the design and analysis?	During the study period, is the intervention administered (or exposure occurred) as intended?
Apra et al (2019)	No	No	No	Yes	Yes
Dogra et al (2022)	No	No	No	Yes	Yes
Frio et al (2019)	No	No	Yes	Yes	Yes
Koutourousiou et al (2013)	No	No	Yes	Yes	Yes
Lucia et al (2024)	No	Yes	Yes	Yes	Yes
Lucia et al (2021)	No	Yes	Yes	Yes	Yes
Mende et al (2020)	Yes	Yes	No	Yes	Yes
Patel et al (2015)	No	Yes	No	Yes	Yes
Rutenberg et al (2022)	Yes	No	No	Yes	Yes
Rutenberg et al (2020)	Yes	No	No	Yes	Yes
Wijnen et al (2017)	No	No	Yes	Yes	Yes
Zhao et al (2021)	No	Yes	Yes	Yes	Yes

Table 5

MMAT Qualitative Quality Appraisal Tool

	Methodological quality criteria				
Author	Is the qualitative approach appropriate to answer the research question?	Are the qualitative data collection methods adequate to address the research question?	Are the findings adequately derived from the data?	Is the interpretation of results sufficiently substantiated by data?	Is there coherence between qualitative data sources, collection, analysis and interpretation?
Daughters et al (2023)	Yes	Yes	Yes	Yes	Yes

1.3.3.2 Textual Narrative Synthesis.

1.3.3.2.1 Pre and Post-Operative Descriptive Characteristics. Firstly, the most reported descriptive characteristics pre- and post-operatively in patients with AOC were cognitive impairment, which included (where specified), memory and neurological difficulties (Apra et al., 2019; Frio et al., 2019; Rutenberg et al., 2022; Rutenberg et al., 2020; Wijnen et al., 2017). Apra et al (2019) gathered pre-operative characteristics for 22 patients. Following the intervention, 18 patients provided an update on their cognitive and social status, with 11% noting major improvement, 83% with stability and a worsening for 6%. Frio et al (2019) reported that 64% of patients with AOC presented with cognitive disorders prior to operation, although cognitive disorder improvement was not reported individually, the total score of cognitive and behavioural disorders improvement after the intervention was 44%. Likewise, cognitive and memory changes at presentation were observed in 16% and 18% of the samples in Rutenberg et al (2022) and Rutenberg et al (2020), respectively. Wijnen et al (2017) found that 27% of patients presented with neurological deficits and saw a reduction of 5% in patients with these deficits over the long term, leaving 22% of patients presenting with neurological deficits. Furthermore, Wijnen et al (2017) also reported on cognitive impairment in the same sample, finding that 16% of patients presented with cognitive impairment and there was an increased incidence of cognitive impairment, with 22% of patients identified.

Secondly, behavioural and personality changes were reported by researchers in four of the papers chosen for review (Frio et al., 2019; Rutenberg et al., 2022; Rutenberg et al., 2020; Wijnen et al., 2017). Pre-operatively, Frio et al (2019) found that 9% of patients presented with behavioural disorders, however, they did not report post-operative improvement individually for behaviour disorders, they simply noted the improvement for both cognitive and behaviour disorders combined, finding a 44% improvement. Frio et al (2019) also found that 9% of patients presented with comorbid cognitive and behavioural disorders. Rutenberg et al (2022) found that at presentation 6% of patients with AOC were presenting with personality changes. Furthermore, Rutenberg et al (2020) found that 7% of patients presented with personality changes comorbid with behaviour changes. Wijnen et al (2017) looked at presenting symptoms of patients with AOC, finding that 11% of patients had behavioural changes. Following the intervention, long-term health conditions were noted, with 19% of patients recognising behavioural changes.

Two studies reported on psychiatric characteristics, and where the researchers were specific, they included depression and pseudo-dementia (Apra et al., 2019; Wijnen et al., 2017). In the sample of Apra et al's (2019) study, 18% of patients pre-operatively presented with signs of depression or "slowing down". Apra et al (2019) reported psychiatric traits and pseudo-dementia relevant to the pre-operative grade of the tumour. Those patients with AOC with a grade 0-1 tumour did not experience any change in psychiatric traits or pseudo-dementia. However, patients with a grade 2 tumour had lower numbers of psychiatric traits and pseudo-dementia post-operatively. Wijnen et al (2017) found that postoperatively, 23% of patients presented with a psychiatric condition when long-term health conditions were being explored.

With regard to employment, two studies reported descriptive characteristics. Apra et al (2019) reported that pre-operatively 50% of patients with AOC were working, 36% had retired and 14% of patients had stopped working. This study did not report employment post-operatively. However, Lucia et al (2024) reported that post-operatively 53% of patients with AOC returned to work. Two studies reported on the mental status at the initial clinical presentation of patients with AOC when they sought diagnosis and treatment. Koutourousiou et al (2013) reported that 2% of patients reported mental changes, and Dogra et al (2022) reported that 10% of patients presented with altered mental status. Neither study provided examples or explanations of the mental changes or altered mental status that were noted. Furthermore, neither study reported if these mental changes persisted following treatment.

Only one study referred to the presence of eating disorders in those individuals with AOC (Mende et al., 2020). The study reported the pre- and post-operative presence of anorexia and polyphagia. It was found that 3% of patients presented with anorexia prior to the operation, and this was reduced to 1% of patients following the operative intervention. Also, 5% of patients presented with polyphagia prior to the operation, and after the operation, 5% of patients presented with polyphagia. Lastly, just one study reported on post-operative independence in activities of daily life. Lucia et al (2021) found that 78% of patients with AOC were independent in their activities of daily living.

1.3.3.2.2 Quality of Life. Of the studies included in the review, three assessed the quality of life in patients living with AOC with the use of a standardised measure (Lucia et al, 2021; Mende et al, 2020; Patel et al, 2015). Both Lucia et al (2021) and Mende et al (2020) used the EORTC QLQ-C30 (Aaronson et al., 1993) to assess the quality of life. The EORTC QLQ-C30 assesses health-related quality of life in general cancer patients that incorporates assessment of functioning, symptoms, global health status, and financial impact of diagnosis. Lucia et al (2021) compared the scores of patients with AOC with a healthy population that was age-matched. Long-term follow-up showed quality of life was lower in the sample with AOC than in the matched controls. However, this difference was not statistically significant. Patients with craniopharyngioma had lower scores in the physical, cognitive and social functional scales. Those patients with the lowest quality of life score had reported newly onset anosmia and ageusia following intervention. Mende et al (2020) compared data with a control cohort of primary brain tumour patients, finding no significant differences in scores when considering functional and symptom scales. When comparing patients with AOC to a cohort of mixed brain tumour patients, those with AOC scored worse than other brain tumour patients, finding significant differences in bladder control, drowsiness and itchy skin scales. Mende et al (2020) also compared results for patients with AOC with a healthy patient cohort, a high level of impairment was found in patients with AOC before and after the intervention, these differences were significant in all areas apart from nausea following surgery. In addition to the above measure, Mende et al (2020) also utilised the EORTC QLQ-BN20 (Aaronson et al., 1993). The EORTC QLQ-BN20 is a supplementary measure module, to be employed in conjunction with the QLQ-C30. The QLQ-BN20 module is designed for patients undergoing radiotherapy and chemotherapy and explores areas such as future uncertainty, visual disorder and communication deficit. When looking at paired data records on the EORTC OLQ-BN20 before and after surgery, there was a significant decrease in future uncertainty, visual disorders and headaches for patients with AOC.

In addition to investigating the quality of life, Patel et al (2015) measured the level of independence of patients using the Wen classification system (Wen et al., 1989). At long-term follow-up, the average level of independence decreased (increase in Wen score), meaning a higher number of patients were less independent. A statistically significant decrease in quality of life measured by the ASBQ (Gil et al., 2004) was associated with a decrease in independence (increased Wen score). The ASBQ is a tool for assessing the quality of life in patients with tumours located in the anterior skull base. It assesses areas such as nasal and visual function. A better quality of life on the ASBQ was found in patients who had gross total resection and post-operative radiation; however, this was not statistically significant. The SNOT-22 (Hopkins et al., 2009) is a measure to assess the social and emotional consequences of a nasal disorder and explores how problematic various areas are, such as, “ear fullness” and “blockage/congestion of the nose”. The use of the SNOT-22 found a statistically significant better quality of life in patients who had gross total resection. Patients with initial post-operative improvement in their vision had better quality of life, but this was not significant. Both the ASBQ and SNOT-22 found improvement in quality of life in the long-term post-operatively compared with pre-operatively, however, these differences from pre- to post-operative were not statistically significant. There was a statistically significant difference between the quality of life of craniopharyngioma and pituitary macroadenoma patients when measured by the ASBQ, finding those with craniopharyngioma have worse quality of life. However, at over 12 months postoperative, the SNOT-22 score was higher for the craniopharyngioma patients than the pituitary macroadenoma patients (a higher SNOT-22 score indicates lower quality of life) however the difference was not statistically significant.

1.3.3.2.3 Psychiatric Disorders and Psychosocial Stressors. Two of the 13 studies included in this review used standardised measures to assess psychiatric disorders and psychosocial stressors for patients with AOC (Lucia et al., 2024; Zhao et al., 2021). Zhao et al (2021) utilised the NPI-Q (Cummings et al., 1994), which provides an assessment of neuropsychiatric symptomatology across 10 domains, considering the severity of the symptom and caregiver distress as a result of the symptom. Examples of the domains include hallucinations, anxiety and disinhibition. The NPI-Q was utilised by Zhao et al (2021) to assess psychiatric disorders in patients with AOC who had undergone surgery. The NPI-Q found that the prevalence of psychiatric disorders in the sample was 15%, and patients presented with at least one psychological symptom after surgery (Zhao et al., 2021). The most common symptoms were irritability, agitation and delusion, whilst other symptoms such as depression and anxiety were reported. Those with psychiatric symptoms had significant risk factors that were identified as associated with psychiatric disorders; tumour extension toward and/or into the third ventricle, a tumour size of larger than 7cm^3 and hypothalamic invasion. At six-month follow-up, there was a significant improvement or even disappearance of psychiatric disorders, therefore patients were able to resume activities of daily living.

Lucia et al (2024) utilised the NCCN-DT (National Comprehensive Cancer Network, 2019) to assess psychosocial stressors. The NCCN-DT requests patients indicate distress levels on a thermometer and subsequently indicate problems they experience from a list, including concern areas such as physical, emotional and spiritual. Lucia et al (2024) found that those with hypothalamic involvement had significantly higher scores on the NCCN-DT compared with those patients who had no hypothalamic involvement or hypothalamic displacement/contact. The most expressed difficulties across domains were exhaustion, worry, exercise, sleep and fear. A risk factor for psychiatric disorders and higher levels of psychosocial stress appears to be hypothalamic involvement as this was reported in both studies by Lucia et al (2024) and Zhao et al (2021).

1.3.3.2.4 Integration of Quantitative and Qualitative Findings. Finally, the findings from the one qualitative study (Daughters et al., 2023) included in this review can serve to contextualise some of the findings across the quantitative papers. Patients with AOC may be surprised to be asked about their mental health, in Daughters et al (2023) a patient reported they were never asked about their mental health in appointments with their endocrinologist, and this might show the lack of acknowledgement of mental health difficulties being experienced by those patients with AOC and therefore contributing to the limited number of studies in this area. As identified by Lucia et al (2024) and Zhao et al (2021) hypothalamic involvement was a risk factor for the incidence of psychiatric disorder at presentation and increased occurrence of psychosocial stress. Likewise, Daughters et al (2023) found that clinicians had identified hypothalamic involvement as a factor that determined the severity of patient symptoms. Hypothalamic involvement was understood to lead to difficulty with medical treatment and an increase in the severity of psychological and physical symptoms.

In Daughters et al (2023) interviews, patients and clinicians commonly referred to affective disorders, such as anxiety and depression. Some of the main difficulties identified by patients were “low moods” and “fluctuating moods”. Patients also recognised periods where their mental health took a big dip “I had a period where I was very down”. Firstly, 18% of patients with AOC presented with signs of depression (Apra et al., 2019) and secondly, one of the most common symptoms identified by Zhao et al (2021) when assessing psychiatric disorders in patients with AOC was depression. Furthermore, patients experienced, and clinicians reported, ‘brain fog’ (Daughters et al., 2023). Whilst this was not directly stated in the quantitative research, brain fog can be understood to fall under cognitive difficulties. Cognitive difficulties were identified within five of the quantitative studies included in this present review. The findings suggest some patients improve, while for others cognitive status remains stable and some have worsening symptoms.

Patients recognised that their social networks had shrunk, and their groups of friends had tapered (Daughters et al., 2023). Other studies included in the review stated that patients with AOC had lower scores on social functioning than controls (Lucia et al., 2021), providing support to this qualitative finding. Social status was also reported, with post-operative reports of major improvement, stability or worsening (Apra et al., 2019). These quantitative and qualitative findings suggest some difficulties in various aspects of social functioning as a result of AOC diagnosis and treatment. Moreover, personality changes may occur as a result of tumour development and surgery, 6% and 7% of patients with AOC presented with personality changes (Rutenberg et al., 2022; Rutenberg et al., 2020). To support this, clinicians and patients both reported that changes in personality are common after treatment (Daughters et al., 2024).

Several studies reported the employment status of patients with AOC (Apra et al., 2019; Lucia et al., 2024), the importance of this being reported and explored is highlighted in the quote “…I went back to work…I never really realised how…beneficial that would be on my mental health.” (Daughters et al., 2023). Furthermore, Daughters et al (2023) emphasised the importance of restoration or maintenance of vision for patients with AOC, whilst Mende et al (2020) found that visual disorders significantly decreased after surgery for patients with AOC. This suggests that surgery may be imperative in managing patients' visual difficulties.

Daughters et al (2023) reported that the most common physical symptoms experienced by patients with AOC were weight gain and fatigue, however, Lucia et al (2021) found that there were significant differences between patients with AOC and mixed brain tumour patients in the bladder control, drowsiness and itchy skin scales. It is interesting that the physical symptoms identified by Daughters et al (2023) were not identified within this sample. Likewise, Mende et al (2020) found that there was a significant decrease in headaches following surgery, however, Daughters et al (2023) found that patients in their sample shared that they tended to get more headaches after treatment.

It is important to note that many of the studies included in the literature review relied on self-report when utilising standardised measures. Conversely, Daughters et al (2023) found that patients may struggle to identify their own mental health difficulties at times, therefore, the findings of all studies should be taken with a pinch of salt, and potentially lower levels of mental health difficulties than expected.

1.3.4 Discussion

The purpose of this systematic review was to understand what has previously been investigated and discovered with regard to the psychological well-being and quality of life in patients with AOC. The studies included in this review reported on patients with AOC and their psychological well-being, in a variety of areas. Furthermore, studies included also reported on quality of life, to provide important updates to the review carried out by Castle-Kirszbaum et al (2022). To consolidate this body of knowledge into a more homogenous pattern, a textual narrative synthesis approach was used, and insight has been gained into the psychological well-being of patients with AOC. This systematic review provides introductory evidence that AOC may be associated with a negative impact on psychological well-being and further supporting evidence that AOC negatively impacts quality of life. The majority of studies in this review gathered data when participants first presented with symptoms, and some studies additionally included data following intervention.

1.3.4.1 Limitations of Previous Research. Firstly, numerous studies included for review utilised a retrospective design. It is important to note that data had originally been recorded for reasons other than research, and there may be selection bias present in the data included. With a retrospective design, there is limited control over data collection, and there may be confounding variables present. Secondly, few of the studies included examined psychological well-being in great depth. Many of the studies included in this review did not have a primary aim to explore the psychological impact of a diagnosis of AOC, the psychological information was an additional finding that was included in the publication. Moreover, a number of studies included did not use validated measures of psychological well-being and quality of life. Therefore, the results may lack reliability and validity. Some studies did use standardised measures, but here, there are also limitations to be acknowledged. The standardised measures used were mostly medical-based, they were brief and not best placed to capture in-depth psychological or social challenges experienced by patients with AOC.

Furthermore, many of the studies included recruited patients from just one or two medical centres and had small sample sizes, since craniopharyngioma is a rare tumour, this is expected, but we must be aware of the lower generalisability to the broader population with craniopharyngioma and the higher risk of bias. Also, where studies reported on the presentation symptoms, and not any post-operative symptoms, it cannot be concluded if the symptoms were long-term or well-managed with treatment. Lastly, the literature reviewed within this review is all published in journals that are primarily focused on the medical and physical perspective, such as World Neurosurgery and Journal of Neurosurgery.

1.3.4.2 Strengths and Limitations of This Review. The present review identified and synthesised the existing literature focusing on the psychological well-being and quality of life of patients with AOC. A literature review with a focus on psychological well-being in patients with AOC has not been conducted previously, therefore this review offers new insights into the existing literature. The review successfully synthesised the findings across quantitative and qualitative literature, supporting the development of an enhanced understanding of the experiences of patients with AOC. The researcher was able to further develop their knowledge of the field throughout the review process and a strong argument for the need for the present thesis has been supported.

A limitation of the review is that a meta-analysis of the studies was not possible due to the heterogeneous nature of the studies. The studies explored psychological well-being and quality of life in different ways, with differing designs and measures used. These differences made it difficult to synthesise findings and draw strong conclusions. Numerous methodological limitations impede results in the literature review, and therefore, the reliability of the literature can be questioned. Additionally, due to the nature of the doctorate programme the researcher is completing, only one author was available to conduct the systematic review, increasing the chances of bias, however, the researcher sought regular supervision, but findings and conclusions may have been different if more than one researcher were involved.

1.3.5 Summary

Despite the potential limitations of the literature included in the review and the review process, this review provides an overview of the current research on the psychological impact and quality of life in those patients with AOC. This systematic review draws attention to the lack of existing exploration of psychological health for this specific population, emphasising the critical need for further research into the impact AOC has on the psychological well-being of an individual and their quality of life. This may lead to the development of interventions that foster good mental health and provide patients with AOC with an enhanced ability to cope with life challenges. Psychological health should be considered a critical aspect of managing and supporting patients with AOC, and further research is necessary to determine the psychological needs in this area.

1.4 Rationale for the Present Thesis

The above systematic review identified that there is a dearth of exploration and knowledge on the psychological well-being of patients with AOC, despite there being identified areas where psychological health is commonly impacted. Currently, the use of standardised measures to consider the impact of AOC on specific areas of mental health, such as depression, anxiety and self-esteem is lacking, and it is uncertain how much of an impact this diagnosis has on patients in the long-term. Therefore, the two current studies aim to contribute to the knowledge base by building on the understanding of the psychological impact of AOC. The present studies hope to bridge the considerable gaps within the existing literature. The proposed research will add to the previous medical literature as the two studies seek to quantitatively capture the specific areas of psychological impact using psychological measures specifically designed to capture this information.

This research may have implications for further research, clinical practice and theory. It will highlight areas where further research is required and hopefully lead to the development of models that can be applied to patients with craniopharyngioma. With regard to clinical implications, it is hoped that this research will increase awareness among healthcare professionals of craniopharyngioma. Secondly, the research hopes to emphasise the need to take into consideration psychological well-being when working with patients with AOC, which in turn could lead to better patient care and experience.

1.4.1 Hypotheses and Aims of the Present Thesis

In Study One, a questionnaire study, it is hypothesised that patients with AOC will score significantly higher on measures of mental health disorders compared to matched controls. It is also hypothesised that patients with AOC will score significantly lower on self-esteem, understanding feelings, emotion regulation, resilience and social functioning measures than matched controls. Furthermore, it is hypothesised that patients with AOC will score significantly higher in measures of physical health difficulty and significantly lower in general satisfaction with life. It was also hypothesised that in patients with AOC, their psychological well-being and physical well-being will significantly predict satisfaction with life. In Study Two, an experimental study, it is hypothesised that patients with AOC will rate videos of social interactions as significantly less social and emotional compared to matched controls. In the present research studies, there are two main aims:

1) To quantitatively assess the impact of AOC on patients' mental health and psychological outcomes, in comparison to matched controls.
2) To quantitatively assess if ratings of social and emotional content are impacted by AOC, in comparison to matched controls.

Chapter Two: Methods

2.1 Overview of Chapter

This chapter outlines the chosen methodology for the current research studies. This chapter will explain the epistemology positioning for the two research studies. Then individually each study's participants and research design will be described. Furthermore, the studies' discrete materials, procedures and methods of analysis will be explained. Lastly, the ethical considerations and dissemination plans for both studies are discussed.

2.2 Epistemological Positioning and Justification of Methodology

Researchers hold a theoretical orientation or paradigm in mind when carrying out their work, whether this be conscious or not. Therefore, the researcher in these studies must consider this (Tuli, 2010). Consideration of the epistemological positioning of the present studies will provide background to introduce the study designs later in this chapter. The numerous research paradigms make various assumptions about how the world operates and therefore they guide the way research is conducted (Creswell, 1994). The purpose of research is to develop insight and new knowledge regarding a specific topic (Godwin et al., 2021), as such the present studies aim to develop insight and new knowledge regarding the specific topic of the impact of an AOC diagnosis.

Positivism has been the historically dominant paradigm for social sciences (McGrath & Johnson, 2003) and establishes that reality exists independently of the researcher (Cohen et al., 2007). The realist ontology of positivism is based on the assumption that a sole concrete reality occurs (Park et al., 2020) and an assumption is made that the researcher maintains an objective stance towards the data (Saunders et al., 2009). There are clear limitations with a positivist epistemology, notably the lack of emphasis on the understanding of your own place in the world and how your assumptions and knowledge impact what you bring to your research (Ryan, 2006). A move away from positivism has been prompted due to recognition of neutral knowledge not existing (Ryan, 2006). Therefore, this paradigm did not fit with the present research and the present studies needed to allow for the role of human perspective and error, whilst upholding a commitment to objective measurement and observation (Godwin et al., 2021), which was possible with the use of the post-positivism paradigm. The use of this paradigm allows the individual experience of the researcher to be considered, and furthermore, recognition that the measures included in research and the interpretation of data are impacted by this individual experience. Whilst positivist researchers believe in absolute truth, the post positivists challenge this when considering human behaviour in social science (Wahyuni, 2012).

When considering the epistemology of the present studies, it was vital to consider the motivations for the research, this is an important characteristic of post-positivism epistemology (Habib, 2020). As with post-positivism, the present study aimed to determine averages and trends in the data, to generalise results to a larger population, importantly those adults with craniopharyngiomas. Although AOC is a rare diagnosis, the researchers hope that the findings of the present research can be generalised to the broader population. Whilst doing this, the present study did not conduct research on participants, instead, the research was conducted among the participants, learning with them (Wolcott, 1990). The adult population diagnosed with craniopharyngioma is under-researched and this led to learning with participants throughout the research as novel insights into the experiences of those participants with AOC were gained. The research did not aim to solve the difficulties being investigated, rather it worked towards recognising the complicated nature of life and individuals' experiences within this (Ryan, 2006), which, in turn, will inform future research.

2.3 Study One

2.3.1 Participants

Participants were individuals with a diagnosis of AOC or controls. The sample size for the present study was calculated using G*Power (Faul et al., 2007). A power calculation was carried out, and the stated sample size of 100 participants with AOC and 100 age-and-gender-matched controls would achieve a 90% power to detect a medium effect size with an alpha value of 0.05.[2] In Study One, 36 participants with AOC were recruited and 41 age- and gender-matched controls Of the 36 AOC participants, 31% were male, and 37% of the controls were males. As mentioned in the pre-registration of the study (https://aspredicted.org/rfsg-445h.pdf), the researchers aimed to recruit 100 participants with AOC, however, recruitment proved challenging. The researchers agreed to exhaust all options as detailed below and complete data collection when necessary. The challenges of recruitment will be explored in chapter four.

All participants were adults over 18 years old, who had either been diagnosed with AOC or were controls. Due to recruitment difficulties, two participants had been diagnosed with COC but took part in the research as adults. An initial email was sent to participants on an existing database of >450 individuals who previously took part in AOC research and self-identified as having AOC. These individuals had consented to be contacted in the future to participate in further research opportunities. The email that was sent included a link to the first survey to establish inclusion or exclusion from the study. The researcher attempted to email a total of 455 self-identified patients with AOC; 415 emails were successfully delivered and 40 were undeliverable for several reasons. Reminder emails were sent to all on the database, but uptake remained low.

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[2] Due to AOC being a rare disease, recruitment proved challenging, and the best effort possible was made in the time frame that was available for this thesis.

Due to the low uptake of participants from this existing database, various charities and organisations were contacted to request advertisements via their websites or social media channels. Those that responded and agreed to advertise were (a) The Pituitary Foundation (the leading national charity for pituitary patients in the United Kingdom); (b) The Three Tumours; (c) The Raymond A Wood Foundation; (d) The Brain Tumour Charity. Moreover, the researcher joined Facebook groups, and, with approval from the administrator of the group, posted an advert to the survey (see Appendix A). These groups included (a) Craniopharyngioma Group Adult Survivors; (b) Craniopharyngioma UK; (c) Craniopharyngioma Australia and New Zealand; (d) Craniopharyngioma Support Group. Lastly, snowball sampling was used and participants with AOC who had completed the study were encouraged to inform other eligible patients with AOC about the study.

In total, 60 potential participants uploaded documents to the screening survey to confirm their AOC diagnosis. Ultimately, 45 participants were confirmed as having a diagnosis of AOC, and the study link was emailed to 42 of these. The remaining three documents were duplicates of patients who had already had their diagnosis confirmed. The outstanding 15 uploads were documents where it was not possible to confirm diagnosis (*n* = 12) and pilot document uploads (*n* = 3).

Of the 63 clicks on the study link for patients with AOC, 46 submitted complete responses. Five pilot responses were excluded, and a further four were excluded due to not meeting the criteria for inclusion, for example, a diagnosis of AOC was not confirmed, and data quality checks were not satisfactory (refer to the 2.3.1.1 for details of inclusion criteria). One participant completed the study twice, and therefore only the most recent response was kept. Therefore, in total, there were 36 study responses from participants with AOC that were included in the data analysis. Consequently, from the 42 participants with a confirmed diagnosis of AOC 36 completed the study, resulting in an 85.71% completion percentage.

Control participants were recruited via a well-established online recruitment platform, the Prolific platform (Prolific, 2024). The study link for controls was accessed 44 times. Forty-one participants completed the study. All participants included in the analyses satisfied the requirements for the attention check questions (the data for the three check questions were deleted from the dataset prior to analysis).

2.3.1.1 Inclusion Criteria. Participants that were included in the study had to have received a diagnosis of craniopharyngioma when over the age of 18 years old, therefore having AOC. Participants also needed to be able to provide informed consent to participate in the study. Participants needed to be able to use an electronic device to access the online survey and participate in English. To confirm a diagnosis of AOC, potential participants were asked to provide documentation which evidenced a diagnosis of AOC. This could be in the form of a letter or a report from a healthcare professional. The researchers reviewed the documentation uploaded to ensure that:

- A diagnosis of AOC was stated OR it was clear AOC is being discussed.
- The date of the AOC diagnosis was evident.
- The document was dated.
- The document was signed.

Some documents included clinical characteristics; however, this was not necessary for this information to be included to take part in the study. To select controls, criteria were set in Prolific to match the control's age, gender and nationality to those of the AOC participants.

2.3.1.2 Exclusion Criteria. The following exclusion criteria were followed to ensure accurate and genuine data:

- Removal of any pilot responses.

- Removal of any responses that did not identify as having AOC if an AOC patient, or responses that identified as having any endocrine condition if a control data.
- Removal of any responses from an email address that had not been confirmed as AOC.
- Removal of any responses that did not pass the three attention check questions, by getting two out of three correct.
- Removal of any responses identified as ‘spam’ by Qualtrics.
- Removal of any responses that took under five minutes.
- Removal of any responses that did not complete all consent items.
- Removal of any replicate responses from the same IP address.
- Removal of responses that completed less than 50% of the survey.
- Removal of any response with a high percentage of repetitive responses.

2.3.2 Design

The present survey-based study was a quantitative design. To establish statistically significant conclusions about a population, whilst studying a representative sample of that population, a quantitative design can be used (Lowhorn, 2007). The study was quasi-experimental in that it utilised an established patient group and was between-subjects: participants with AOC or controls. In the present study, physical and psychological consequences are the dependent or outcome variable, and the participant diagnosis (AOC patient or control) is the independent variable.

2.3.3 Materials

Participants were asked to complete 12 questionnaires: one demographic questionnaire and 11 well-validated questionnaires. All measures were screened, and the survey was piloted by five individuals prior to distribution. This pilot enabled minor changes, such as table layout, to be made to the survey prior to participants taking part.

All participants were asked a standard set of questions to gather socio-demographic information, including sex, and age (see Appendix B for complete list). Participants' medical history was required including age at diagnosis, height, weight, tumour type, surgery type, history of radiotherapy and hormone replacement medication (see Appendix C for exact questions). Current height and weight were self-reported by participants.

In the study, all participants completed the same questionnaires measuring mental health, psychological health, physical health, and life satisfaction. These questionnaires were presented in four blocks (a) mental health; (b) psychological health; (c) physical health; (d) life satisfaction. Within the mental health, psychological health, and physical health blocks, the measures were presented in a random order generated by Qualtrics. In the Life Satisfaction block, there was only one measure, and therefore no randomiser was necessary.

Measures included (a) Beck Depression Inventory (Beck & Steer, 1984); (b) Generalised Anxiety Disorder Assessment Tool (Spitzer et al., 2006); (c) Rosenberg Self-Esteem Scale (Rosenberg, 1965); (d) Toronto Alexithymia Scale (Bagby et al., 1994); (e) Emotion Regulation Questionnaire (Gross & John, 2003); (f) 10-item Connor-Davidson Resilience Scale (Campbell-Sills & Stein, 2007); (g) Social Functioning Scale (Birchwood et al., 1990); (h) REACT scale (Robinson & Bacon, 1989); (i) Chalder Fatigue Scale (Cella & Chalder, 2010); (j) Impact of Vision Impairment Scale (Lamoureux et al., 2008); (k) The Satisfaction with Life Scale (Diener et al., 1985). All measures were self-report measures. The internal consistency of all scales was assessed using Cronbach’s alpha and Georgie & Mallery’s (2019) rules of thumb for interpretation were used.

Beck Depression Inventory (Beck & Steer, 1984) is a 21-item self-report rating inventory that measures characteristic attitudes and symptoms of depression over the past two weeks. Each item has four possible responses, ranging in the intensity of the symptom. An example item is (0) I do not feel sad, (1) I feel sad, (2) I am sad all the time and I can't snap out of it, (3) I am so sad or unhappy that I can't stand it. The total possible minimum score is zero, and the maximum is 63. The scores are summed across items, and a higher value across items indicates greater symptoms of depression. Standard cut-off scores are 0-18, indicating minimal depression, 18-30 indicating mild depression, 19-29 indicating moderate depression, and 30-63 indicating severe depression. The measure demonstrated excellent internal consistency (α = .92).

A 7-item brief measure for the assessment of Generalised Anxiety Disorder was used (Spitzer et al., 2006). Each item is rated on a 4-point Likert scale from 0 (*not at all*) to 3 (*nearly every day*). This measure captures experiences over the past two weeks. The measure uses statements such as "feeling nervous, anxious or on edge" and "being so restless that it is hard to sit still". The possible minimum score is 0 and the maximum is 21. The scores are summed across items, and a higher value across items indicates greater symptoms of anxiety. Standard cut-off scores are 0-4 indicating minimal anxiety, 5-9 indicating mild anxiety, 10-14 indicating moderate anxiety, and scores greater than 15 indicating severe anxiety. The measure obtained good internal consistency (α = .87).

Rosenberg Self-Esteem Scale (Rosenberg, 1965) is comprised of 10 items, five of which are negatively worded. Participants with AOC were asked to reflect on the time since their AOC diagnosis or treatment, and controls were asked to reflect on how they had felt over the past year. Each item is rated on a 4-point Likert scale from 1 (*strongly agree*) to 4 (*strongly disagree*). Five items are negatively worded and were reverse-scored. The possible minimum score is 10 and the maximum score is 40. An example of a positively worded item is "on the whole, I am satisfied with myself" and a negatively worded item is "all in all, I am inclined to think that I am a failure". The scores are summed across items, and a lower value across items indicates lower self-esteem. Scores between 25 and 35 are within the normal range, and a score below 15 suggests low self-esteem. The measure obtained excellent internal consistency (α = .91).

The Toronto Alexithymia Scale (Bagby et al., 1994) consists of 20 items that are rated on a 5-point Likert scale from 1 (*strongly disagree*) and 5 (*strongly agree*), with five items negatively worded and reverse scored. Participants with AOC were asked to reflect on the time since their AOC diagnosis or treatment, and controls were asked to reflect on the past year. The scale measures the three dimensions of alexithymia – difficulty describing emotions, difficulty identifying emotions, and the tendency of individuals to focus their attention externally. Items include “I am often confused about what emotion I am feeling” and “I find it hard to describe how I feel about people”. The total alexithymia score is the sum of responses to all 20 items, a minimum of 20 and a maximum of 100. A higher value across items indicates greater symptoms of alexithymia. A total score equal to or less than 51 indicates no alexithymia-related difficulties, 52 to 60 indicates possible alexithymia-related difficulties, and equal to or greater than 61 indicates alexithymia-related difficulties. The measure obtained good internal consistency (α = .89).

A 10-item scale, Emotion Regulation Questionnaire, was designed to measure respondents' tendency to regulate their emotions by cognitive reappraisal and expressive suppression (Gross & John, 2003). Participants with AOC were asked to reflect on the time since their AOC diagnosis or treatment, and controls were asked to reflect on the past year. The measure requests answers on a 7-point Likert-type scale ranging from 1 (*strongly disagree*) to 7 (*strongly agree*). The cognitive reappraisal facet is made up of 6 items, including “when I want to feel less negative emotion (such as sadness or anger), I change what I’m thinking about”. The expressive suppression facet is made up of 4 items, including “when I am feeling negative emotions, I make sure not to express them”. Each facet’s scoring is kept separate, the minimum cognitive reappraisal facet score is six and the maximum score is 42. The minimum expressive suppression facet score is four and the maximum score is 28. The higher the score in a facet, the greater the use of that facet of emotion regulation, and lower scores represent less frequent use. The measure obtained acceptable internal consistency (α = .76).

The Connor-Davidson Resilience Scale is comprised of 10 items (Campbell-Sills & Stein, 2007). Participants with AOC were asked to reflect on the time since their AOC diagnosis or treatment, and controls were asked to reflect on the past year. The scale is structured as a 5-point Likert-type scale from 0 (*never*) and 4 (*almost always*). Items include “I can deal with whatever comes my way” and “under pressure, I stay focused”. The total score on the scale ranges from 0-40. The scores are summed across items, and a higher value across items indicates greater resilience. The measure obtained good internal consistency (α = .88).

The Social Functioning Scale (Birchwood et al., 1990) is a 79-item self-report measure. Participants with AOC were asked to reflect on the time since their AOC diagnosis or treatment, and controls were asked to reflect on the past year. Items assess ability and performance related to social engagement, interpersonal contact, recreation, independence and competence in activities, and activities of daily living and employment. Items include “What time do you get up each day” and “How many friends do you have at the moment”. Responses to items include yes/no, and a variety of Likert scales. The minimum total score is zero and the maximum is 223. The scores are summed across items, and a higher total score indicates better social functioning. The measure obtained excellent internal consistency (α = .91).

The REACT scale (Robinson & Bacon, 1989) is a 48-item self-report measure of how an individual feels about their weight, body shape or size and if these factors prevent engagement in any daily activities. Participants with AOC were asked to reflect on the time since their AOC diagnosis or treatment, and controls were asked to reflect on the past year. Items cover 10 different categories including appearance, health activities and emotions. Items in each category are preceded by the following sentence “How I feel about my weight, body shape or size prevents (or would prevent) me from:”. An example from each category includes (a) vocational/educational “improving my job, position or business” (b) food “buying certain foods at the grocery store” (c) appearance “wearing shorts and/or bathing suits” (d) physical activities/exercise “participating in a health club and/or an exercise class” (e) health activities “eating nutritiously” (f) emotional “feeling liked/accepted by others” (g) social activities “trying to meet new people” (h) dating/relationships “flirting” (i) sexual relationships “letting my/a partner see me naked” (j) miscellaneous “doing something I’ve always wanted to do”. A 5-point Likert-type scale is used for 47 items, ranging from 0 (*never*) to 4 (*always*) and “not applicable”. The final item, number 48, asks participants “Do you consider yourself...?”, with responses ranging from 1 (*underweight*) to 5 (*overweight*). The overall score ranges from 0-188. The scores are summed across items, and a higher value across items indicates greater difficulties. The higher an individual scores, the more restrictions the person is placing on their life due to weight, body shape or size. The measure obtained excellent internal consistency (α = .98).

The Chalder Fatigue Scale (Cella & Chalder, 2010), measures the extent and severity of fatigue experienced by an individual (Jackson, 2015). Participants with AOC were asked to reflect on the time since their AOC diagnosis or treatment, and controls were asked to reflect on the past year. The scale consists of 11 items, assessing the symptoms of fatigue, such as lack of energy and difficulty in concentration and memory. Responses are given on a 4-point Likert scale, from 0 (*less than usual*) and 3 (*much more than usual*). Items include “Do you have problems with tiredness?” and “Do you have less strength in your muscles?”. The possible total score on the scale ranges from 0-33. The scores are summed across items, and a higher value across items indicates greater symptoms of fatigue. A higher score indicates an increased extent and severity of fatigue. The measure obtained excellent internal consistency (α = .92).

The Impact of Vision Impairment Scale (Lamoureux et al., 2008) assesses the impact of vision loss on daily life and activities. Participants with AOC were asked to reflect on the time since their AOC diagnosis or treatment, and controls were asked to reflect on the past year. It is a 28-item measure, with items using a 4-point Likert-type scale from 0 (*not at all*) to 3 (*a lot*). The scale has a 3-subscale structure of emotional well-being, reading and accessing information, and mobility and independence. Participants respond to each item, indicating how much their vision impacts their ability to engage in the activity. Examples of items include “your ability to see and enjoy TV”, “visiting friends or family”, and “Have you felt embarrassed because of your eyesight?”. All participants were provided with a relevant example, the example for participants with AOC was “If your vision since your AOC treatment has had a significant impact on your ability to see and enjoy TV, you might select "A lot".”. The score ranges on the scale from 0 to 84.[3] The scores are summed across items, and a higher value across items indicates a greater impact of vision loss on daily life and activities. The measure obtained excellent internal consistency (α = .98).

To measure global cognitive judgements of one’s life satisfaction, the Satisfaction with Life Scale (Diener et al., 1985) was used. Participants with AOC were asked to reflect on the time since their AOC diagnosis or treatment, and controls were asked to reflect on the past year. This scale consists of five items, and participants must indicate how much they agree or disagree with the items. The items include “In most ways, my life is close to ideal”

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[3] Two items should have been on a 3-point Likert scale but were accidentally coded with the same 4-point Likert scale as other items. However, the two items hold well with the structure, and were retained are coded.

and “I am satisfied with my life”. The items are scored on a 7-point Likert-type scale whereby 1 (*strongly disagree*) and 7 (*strongly agree*). The scores can be summed, with a minimum total score of five or a maximum total score of 35. The scores are summed across items, and a higher value across items indicates greater satisfaction with life. A cut-off score of 5-9 indicates extremely dissatisfied, 20 is neutral and 31-35 indicates extremely satisfied. The measure obtained good internal consistency (α = .88).

2.3.4 Procedure

Potential patients with AOC were sent an email and they were able to click on the initial survey link. This initial survey link presented potential participants with the Participant Information Sheet (see Appendix D). There were two versions of the Participant Information Sheet, one for patients with AOC and one for controls. This informed participants of the purpose of the research, confidentiality, the voluntary nature of participation and the right to withdraw. To establish inclusion or exclusion from the study, potential participants were asked to upload evidence confirming a diagnosis of AOC. The document could be uploaded in a variety of formats. Lastly, potential participants were asked to provide an email address so that researchers could communicate if they were eligible to participate in the experimental survey. The documentation was initially reviewed by the research supervisor, an expert in the field, to confirm if the inclusion criteria had been met. As the principal researcher became familiar with this process, they were able to review the documentation and confirm a diagnosis. Those participants who met the inclusion criteria were emailed with a link to the experimental survey. Those participants who uploaded documentation where it was not possible to confirm a diagnosis of AOC were emailed requesting that they contact the researchers if they believed that they did have a diagnosis of AOC. The initial link was also included in this email so that participants could re-upload documentation if necessary.

For eligible AOC participants, the experimental survey link was sent via email, and controls signed up for the study on Prolific and followed the survey link from the platform. For all participants, the survey was presented via Qualtrics, and it presented a reCAPTCHA (Completely Automated Public Turing test to tell Computers and Humans Apart) to prevent automatic programs from proceeding and attempting to complete the survey (Von Ahn et al., 2008). Following the successful completion of the reCAPTCHA, the Participant Information Sheet was presented, and participants were asked to confirm that they had read this. A further four consent questions were asked (see Appendix E). If participants did not agree to all five consent statements, then they were not eligible to take part and were taken to the end of the survey. If consent statements were agreed to, then the survey collected demographic information. Only participants with AOC were asked specific questions about their diagnosis of AOC. The survey presented outcome measures in four blocks:

1. Mental health.
2. Psychological health.
3. Physical health.
4. Satisfaction with life.

The presentation of the 4 blocks was in a fixed order for all participants. The outcome measures within the blocks were randomised to allow for best scientific practice to eliminate order effects. At the end of the survey, participants were provided with signposting for mental health support in various forms, such as telephone calls, text messages, or emails.

Lastly, participants with AOC were asked for their email addresses to allow compensation for their participation to be sent via email. Once satisfactory completion of the study was confirmed and data quality control was conducted, an email with an Amazon voucher code (of the value of £10 or $10) and instructions on how to redeem the voucher was sent to all AOC participants. Controls were compensated and paid directly via Prolific with a bank transfer of £10 or $10.

2.3.5 Method of Data Analysis

The data was exported from Qualtrics to Microsoft Excel with the use of labels to confirm each participant's data met the inclusion and exclusion criteria. Data preparation was carried out in Microsoft Excel, which included (a) deletion of unnecessary rows[4] and columns;[5] (b) deletion of test questions data; (c) ensuring a single row of variable names in row one with acceptable variable names; (d) data that was qualitative (such as, a participant typing 7 am[6] as their wake up time) was quantitatively scored manually according to the official scoring guide. Once data preparation was complete, the data for participants with AOC and controls were combined into one Microsoft Excel document.

Data was then imported from Excel into IBM SPSS Statistics (Version 29), ready to be analysed. To understand the sample from which data was collected, demographics and participant characteristics were described, as well as the means, ranges, and standard deviation. Data from participants' medical records was obtained to look at differing physical and mental health profiles of participants with AOC and controls. The total scores for each measure were used in this study.[7] The internal consistency and distribution of data on each measure were checked.

To address the first and second hypotheses, independent samples *t-tests* were used to compare the means of the two groups: participants with AOC and controls, and determine any

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[4] One participant with AOC completed the survey in March and August 2024, the most recent data input was included in the data analysis.

[5] The researcher incorrectly included SFS_Ip_8 twice, therefore the second response was simply dropped from analysis.

[6] One control was a night shift worker, and their data on the SFS regarding wake time were excluded from the data analysis.

[7] Subscale scores are available for some measures; however, these were not used in the present study due to the existing number of analyses.

significant differences. The final hypothesis was explored with the use of multiple linear regression. Two multiple linear regressions were run using the data from participants with AOC.[8] The dependent variable was satisfaction with life in both regressions. In the first, the independent variables were psychological health predictors, and in the second, the independent variables were physical health predictors. The multiple linear regressions were run to indicate the proportion of variance in life satisfaction explained by, firstly, the psychological health predictors, and secondly, the physical health predictors.

In the pre-registration, it was stated that, firstly, data would be stratified according to treatment history, hormone replacement therapy and age at diagnosis and secondly, that mediation analysis would be conducted. However, due to the lower-than-expected sample size, the researchers decided not to run this analysis.

2.4 Study Two

2.4.1 Participants

Participants were individuals with a diagnosis of AOC or controls. The sample size for the present study was calculated using G*Power (Faul et al., 2007). A power calculation was carried out, and a sample size of 100 patients with AOC and 100 controls would have achieved a 90% power to detect a medium effect size with an alpha value of 0.05. In Study Two, 19 participants with AOC were recruited and 20 age and gender-matched controls. Out of a total of 19 participants with AOC, 100% previously took part in Study One. The data of the controls was anonymous, and they were recruited in December 2024,[9] therefore, it is unlikely the controls are the same controls as in Study One. Of the 19 AOC participants, 42% were male and 45% of controls were male. The study was pre-registered on AsPredicted

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[8] The pre-registration stated that multiple linear regressions would only be run on the data from participants with AOC.

[9] Study One controls were recruited in July 2023 and November 2024.

(https://aspredicted.org/qyq6-bd8v.pdf) after the collection of data from six AOC participants in order to assess which outcome variables would be used.

The study link was accessed a total of 99 times with 41 complete responses submitted. Of the submitted responses, 20 were that of participants with AOC and 21 were that of controls. Data was excluded from one participant with AOC due to being identified as 'spam' by the researcher, and one control participant due to them identifying that they have an endocrine condition. Therefore, data from 19 participants with AOC and 20 controls was available for data analysis. The 36 participants with AOC who successfully completed Study One were sent an invitation to participate in Study Two, therefore the dropout rate of participants with AOC from Study One to Two was 47.22%.

2.4.1.1 Inclusion Criteria. The following criteria were used to select the patients with AOC to participate in the study. The patients with AOC had previously provided satisfactory evidence of an AOC diagnosis to participate in Study One. Controls were included if they matched the age, gender and nationality of participants with AOC.

2.4.1.2 Exclusion Criteria. The following exclusion criteria were followed to ensure accurate and genuine data:

- Removal of any pilot responses.
- Removal of any responses that did not complete all consent items.
- Removal of any responses from an email address that had not been confirmed as AOC diagnosis.
- Removal of any responses that did not identify as having AOC if an AOC patient, or responses that did identify as having an endocrine condition if a control.
- Removal of responses that completed less than 50% of the experiment.

- Removal of any response with a high percentage of repetitive responses to each video clip.

2.4.2 Design

A quantitative design was employed for the present study. An experimental-based study was used to investigate different ratings of emotional and social content for social interaction videos between the two participant groups. The study was quasi-experimental in that it used an established patient group and used a between-subject design. All participants took part in the same conditions, watching the same video stimuli. In the present study, emotional and social content scores are the dependent or outcome variable, and the participant diagnosis (AOC patient or control) is the independent variable.

2.4.3 Materials

The study used novel stimuli that were created and validated for a previous study (Landsiedel et al., 2022). The stimuli were 60 4-second video clips, showing various everyday scenarios. Each scenario was either a social interaction or non-interaction (acting independently) between two individuals. Fifty percent of the video clips showed a social interaction and 50% showed a non-interaction. The video clips of social interactions and non-interactions were matched as carefully as possible, including the same action, props, and consistent average physical space between the two individuals in the video clip. Scenarios were performed across eight different geographical localities. Four different actor pairings performed the scenarios (a) two female/female pairs; (b) one male/male pair; (c) one female/male pair. The videos did not have audio to avoid any confounding variables. Landsiedel et al (2022) can be referred to for further information about the novel stimuli used.

Participants were required to use a laptop or desktop computer to complete the study. They also were required to use a keyboard to type a free text response, and to press the up arrow on the keyboard to continue to the next video.

The study was piloted four times prior to distribution. This pilot enabled the researchers to make minor changes, such as the inclusion of a midway break, to be made to the study prior to distribution to participants.

2.4.4 Procedure

The participants with AOC who satisfied the inclusion criteria for Study One and had successfully completed the study were then invited to take part in Study Two. An email was sent from the researcher inviting the participant to take part in a further study about AOC. The link to take part in the study was included in the email. Control participants were recruited via Prolific.

The experiment was created in PsychoPy 3 (Peirce et al., 2019) and presented online via Pavlovia (https://pavlovia.org/). Firstly, participant demographics were requested, and then a Participant Information Sheet (see Appendix F) was presented, followed by five consent statements (see Appendix G). As with Study One, all consent statements had to be 'ticked' to proceed with the study. Participants then watched the videos, after each video they were asked to describe what they thought was happening in as much detail as possible. After 30 video stimuli had been presented, participants were presented with a screen allowing them to take a short break from the experiment. The final 30 video stimuli were then presented following the participant completing their break. At the end of the study, participants were presented with a debrief screen, including the researcher's email address in case of any questions. Lastly, participants with AOC were asked for an email address so that a compensation voucher could be sent to them. Once satisfactory completion of the experiment was confirmed and data quality control was complete, AOC participants were sent an

Amazon voucher for completing the experiment, this was either £10 or $10. Control participants were paid either £10 or $10 via bank transfer via Prolific.

2.4.5 Method of Data Analysis

To provide a description of the sample from which data was collected, descriptive statistics including age and sex were described. The short text data generated during the experiment in response to the video stimuli was downloaded and prepared in Microsoft Excel. In Microsoft Excel, the data from each individual participant was separated into two separate sheets, one sheet containing the social interaction responses, and the other containing the non-interaction responses. The prepared data was then copied into Linguistic Inquiry and Word Count (LIWC) to analyse the written content for psychologically meaningful categories of language (Boyd et al., 2022). The LIWC software used over 100 built-in dictionaries to capture social and psychological states. The LIWC software calculates the number of words related to a category and then converts these numbers to percentages (Boyd et al., 2022). A higher percentage indicates a higher use of the words in the LIWC dictionary related to that specific category. A percentage was calculated for each short text answer. The percentages across all social interaction videos were averaged in preparation for analysis.[10]

The pre-registration identified 15 categories to be explored in data analysis including (a) affect; (b) angry emotion; (c) anxious emotion; (d) communication; (e) emotion; (f) feeling; (g) negative emotion; (h) negative tone; (i) positive emotion; (j) positive tone; (k) pro-social behaviour; (l) sad emotion; (m) social; (n) social behaviour; (o) tone. A variety of words are associated with each category (Boyd et al., 2022), for example:

- The communication category most frequently used exemplars are (a) said; (b) say; (c) tell.

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[10] Averages were used due to some participants not responding to all 60 videos.

- The social category most frequently used exemplars are (a) you; (b) we; (c) he; (d) she.
- The emotion category most frequently used exemplars are (a) good; (b) love; (c) happy; (d) hope.

Data from the stated categories were then analysed in IBM SPSS Statistics (Version 29). To address the hypothesis relating to Study Two, independent samples *t-tests* were used to compare the means of the two groups: participants with AOC and controls, and determine any significant differences. The researchers made the decision not to analyse the data for the non-interaction videos as it was not expected that there would be a difference in response to these videos. It was not appropriate to average percentages across all video stimuli, as this may have masked any differences.

2.5 Ethical Considerations

Both studies were approved by the University of Essex Ethics Committee (ETH2223-0389; ETH2324-0166) (see Appendix H). As such, the research was conducted in accordance with the ethical guidance of The University of Essex. Participants were recruited outside of the National Health Service via a pre-existing participant database, or advertisement via charities, organisations or social media. Participants were also recruited via Prolific; therefore, only local ethical approval was required.

It was important that the British Psychological Society (BPS) ethics guidelines for internet-mediated research were referred to (BPS, 2023) given that the studies were carried out online. Firstly, following the presentation of the Participant Information Sheet, informed consent was sought. In Study One, participants had to select “I agree” to all five consent statements. In Study Two, a “tick” box had to be selected for all five consent statements. In both studies, a response was required to continue with the study. Secondly, participants were informed that their participation was voluntary and that they had the right to withdraw from the study. Participants were made aware that any data recorded up until their withdrawal would be included in the analyses. Furthermore, participants were given the contact details of the researchers in the initial email, in the Participant Information Sheet and at the end of the survey should they have liked to make contact or ask any questions.

The potential for physical, social, and psychological harm was kept to a minimum, but there is potential for emotional distress, due to the emotive topics asked about in the various measures. To mitigate this potential for harm, information about mental health support available was provided at the end of the study. Participants had the option of seeking support through a variety of sources that best suited their individual needs.

2.6 Dissemination

The aim will be to share outcomes with as many individuals as possible, given the novel contribution to the field and the importance of the research findings. The External Relations and Communications Team at the university can support any public engagement activities. Firstly, the present research studies have been written up in the form of a thesis which will be available on the University of Essex's Research Repository, an open access institutional repository. Secondly, the study results will be disseminated via email to participants with AOC, as previously requested by several participants with AOC. Also, the researcher will present findings at the University of Essex's Health and Social Care Staff Student Research Conference and Essex Partnership University NHS Foundation Trust Psychological Services Conference. Both are scheduled to take place in June 2025.

Furthermore, the Pituitary Foundation will be approached with the hopes of attending and presenting at online or in-person events, requesting an article to be included in the "Pituitary Life Magazine" distributed three times a year and/or writing an article for the 'news and updates' webpage. Additionally, The Endocrinologist Editorial office will be contacted to express interest in writing an article for the next issue of their magazine. This national magazine has a clinical, academic and non-academic audience.

Moreover, the presentation of the research and findings will take place through attendance at academic conferences. The researcher plans to submit the abstract to the various conferences of interest including those with a psychological focus (e.g., International Conference on Psychology) and endocrine focus (e.g., International Conference on Endocrinology). Also, research will be published in high-impact, open-access journals in both the field of psychology (e.g., Journal of Health Psychology, International Journal of Clinical and Health Psychology) and endocrinology (e.g., Journal of Clinical Endocrinology and Metabolism). We hope to measure the impact of dissemination by obtaining data regarding the readership of magazine issues, event attendance and citations and downloads of research.

Chapter Three: Results

3.1 Chapter Overview

The chapter sets out the research findings of the two studies conducted. Study One will be presented first, followed by Study Two. For each study, the statistical assumptions are discussed first, followed by the demographics and participant characteristics, and a discussion of the distribution of the relevant data. Finally, the inferential statistics are reported.

3.2 Assumptions of Statistical Tests

It is essential to check the assumption of normality prior to any statistical analyses of data (Das et al., 2016). The Kolmogorov-Smirnov test for goodness of fit (Massey, 1951) statistic was reported for each measure and category, and a significance level of 0.05 was used when interpreting the results of the test. However, it is important to note that it has been recognised that the Kolmogorov-Smirnov goodness-of-fit test can be "much too conservative" leading to *p* values being strongly biased upward (Steinskog et al., 2007, p. 1151), therefore other methods were used to judge normality.

It has previously been recognised that visual inspection for the normality of data by researchers may be preferable (Orr et al., 1991) and that the use of graphical methods offers support with decision-making (Chambers, 1983). These graphical methods include histograms and quantile-quantile (Q-Q) plots. A histogram can provide a visual approximation of whether the distribution of data is normal, depicted by a bell shape. The Q-Q plots can show a normal distribution whereby quantiles of one distribution are plotted against quantiles of a normal distribution. If a curve is present this can indicate skewness of the data (Das et al., 2016).

Additionally, asymmetry can be measured by skewness, a curve may appear distorted or positively and negatively skewed (Kwak & Park, 2019). A perfect normal distribution would be characterised by a skewness value of zero. If the skewness value falls between -1 and 1, then a distribution can be considered approximately normal. A skewness between -0.5 and 0.5 categorises data as symmetrical, and moderate skewness is considered between -1 and -0.5 and 0.5 and 1. Highly skewed is categorised with a skewness value of less than -1 or above 1 (Bulmer, 2012).

The statistical analysis method of an independent samples t-test is a manner to compare the means of two independent variables (Kwak & Park, 2019) when normality is assumed. The statistical analyses in this chapter were conducted with the use of a significance level of 0.05, indicating a 95% confidence level that the observed result is statistically significant (Fisher, 1934). The two groups being compared were independent of each other and normality was checked prior to the t-test. Homoskedasticity was checked and Levene's Test for Equality of Variances were mostly non-significant and equal variance assumption was met. On occasions that this assumption was not met, further details are provided later in this chapter. Where it is not possible to complete a parametric test, the non-parametric alternative to an independent samples t-test, the Mann-Whitney U-test was used. The Mann-Whitney U-Test can compare independent group data when data is not normally distributed. This test checks whether the distributions of the ranks of the data from the two groups are the same (Kwak & Park, 2019).

A multiple linear regression is used to calculate the relationship between the dependent variable and numerous possible explanatory variables and also the estimated regression model assesses the explanatory power of each of the variables on the dependent variable (Kwak & Park, 2019). Regression assumes normality, linearity, homoscedasticity and independence (Kwak & Park, 2019). Osborne & Waters (2019) state firstly, that normality is important as the inclusion of non-normally distributed data can mislead significant tests. Secondly, a relationship must be linear in nature, if this is not true, then the true relationship will be underestimated. In the below analyses, the Variance Inflation Factor (VIF) is referred to in order to check for multicollinearity. O'Brien (2007) argues that a VIF of over 5.0 can be problematic, and multicollinearity is a potential concern. Also, homoscedasticity is assumed, meaning that across all levels of the independent variable, the variance of errors is the same and the model's predictions are unbiased and reliable (Fox, 2015). Lastly, the Durbin-Watson statistic is also useful to determine whether there is autocorrelation in the model. Values from one to three are acceptable for the Durbin-Watson statistic, suggestive of no autocorrelation (Gujarati, 2002).

3.3 Study One

3.3.1 Demographics and Participant Characteristics

3.3.1.1 Age, Age at Diagnosis and Sex. Participants with AOC had a mean age of 39.33 years and controls had a mean age of 43.07 years (Table 6). An independent samples t-test confirmed that there was no significant difference in age of the participants with AOC (*M* = 39.33, *SD* = 12.55) and controls (*M* = 43.07, *SD* = 13.00), *t*(75) = -1.28, *p* = .205.

The mean age of diagnosis for participants with AOC was 34.72 years old. Two participants with COC were included in the data, the age of diagnosis was 12 and 17 years old. If the COC cases were not included, the mean age of diagnosis was 35.91 years, with a minimum age of 19 and a maximum of 67 years old.

A chi-square test of independence was performed to evaluate the relationship between participant group and sex (Table 6). The relationship between these variables was not significant, $\chi^2(2, N = 77) = 1.30, p = .523$. This revealed no significant association between participant group and sex.

3.3.1.2 Country of Residence. Of the participants with AOC (*n* = 36), the majority (86%) were from the United Kingdom of Great Britain and Northern Ireland or United States of America. Refer directly to Table 6 for full details. Of the controls (*n* = 41), all participants were from the United Kingdom of Great Britain and Northern Ireland or the United States of America (Table 6).

Table 6

Study One Participant Demographics

	AOC	Control
Age (years)	39.33 (20 – 75)	43.07 (21 – 67)
Age of Diagnosis (years)	34.72 (12 – 67)	-
Participant Sex		
Male	11 (30.6%)	15 (36.6%)
Female	25 (69.4%)	25 (61.0%)
Prefer not to say/Non-Binary/Third Gender	-	1 (2.4%)
Total	36	41
Country of Residence		
United Kingdom of Great Britain and Northern Ireland	20 (55.56%)	30 (73.17%)
United States of America	11 (30.56%)	11 (26.83%)
Canada	2 (5.56%)	-
New Zealand	1 (2.78%)	-
Republic of Ireland	1 (2.78%)	-
Jordan	1 (2.78%)	-
Total	36	41

3.3.1.3 Height and Weight. Male participants with AOC had an average height of 5 feet 9 inches, and male controls had an average height of 5 feet 11 inches (Table 7).

Participants were asked to report weight in stones and pounds. If participants reported weight in kilograms or pounds, this data was converted; however, some participants did not state a measurement for their weight, so this data was excluded. This led to missing data for six participants with AOC and three controls. On average, the 30 participants with AOC had a weight of 13 stone 1 pound, and the 38 controls weighed 12 stone 9 pounds (Table 7).

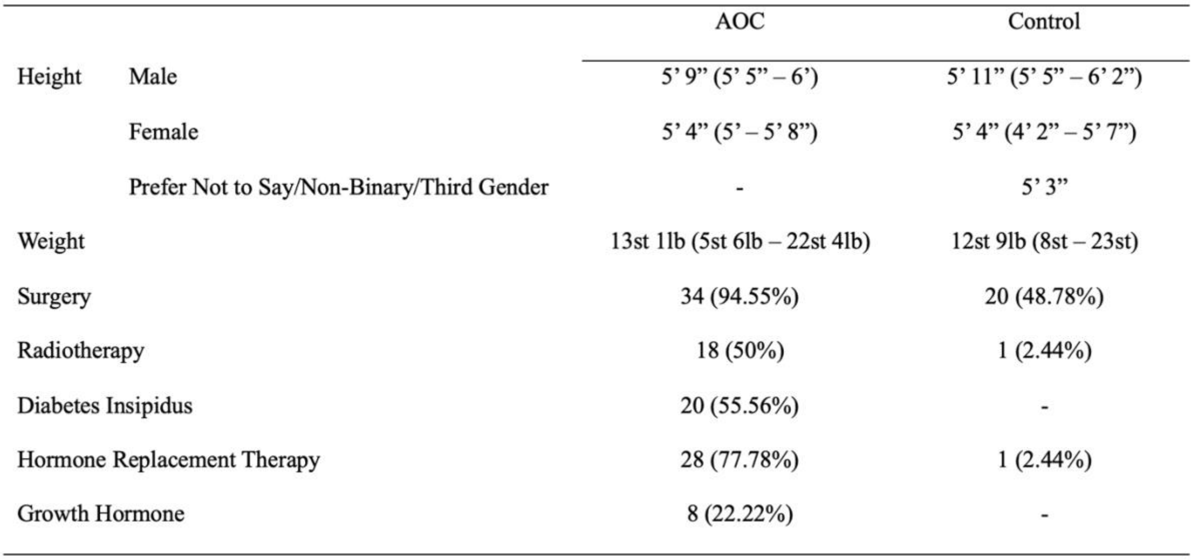
3.3.1.4 Surgery and Radiotherapy. The majority of participants with AOC reported having surgery and half reported having radiotherapy as an intervention for AOC (Table 7).

All participants with AOC who had radiotherapy also had surgery, apart from one participant. A lower percentage of controls reported having surgery and radiotherapy. The control's reasons for surgery and radiotherapy did not include endocrine conditions or brain tumours.

3.3.1.5 Hormone Replacement, Diabetes Insipidus and Growth Hormone. Twenty-eight participants with AOC reported taking hormone replacements, 20 participants with AOC reported taking medication for Diabetes Insipidus, and eight participants with AOC reported taking growth hormone. A much lower number of controls reported taking hormone replacements. No controls reported taking growth hormone or medication for Diabetes Insipidus.

Table 7

Study One Participant Physical Health



		AOC	Control
Height	Male	5' 9" (5' 5" – 6')	5' 11" (5' 5" – 6' 2")
	Female	5' 4" (5' – 5' 8")	5' 4" (4' 2" – 5' 7")
	Prefer Not to Say/Non-Binary/Third Gender	-	5' 3"
Weight		13st 1lb (5st 6lb – 22st 4lb)	12st 9lb (8st – 23st)
Surgery		34 (94.55%)	20 (48.78%)
Radiotherapy		18 (50%)	1 (2.44%)
Diabetes Insipidus		20 (55.56%)	-
Hormone Replacement Therapy		28 (77.78%)	1 (2.44%)
Growth Hormone		8 (22.22%)	-

Note. ' = feet, " = inches, st = stone, lb = pounds

3.3.1.6 Vision. Of the participants with AOC, over 50% reported some visual disturbances as a result of their AOC diagnosis and/or treatment (Figure 3). Of the controls, over 50% reported corrected-to-normal vision (Figure 4). In contrast with participants with AOC, no controls reported severe visual disturbances or "other".

Figure 3

Vision of AOC Participants

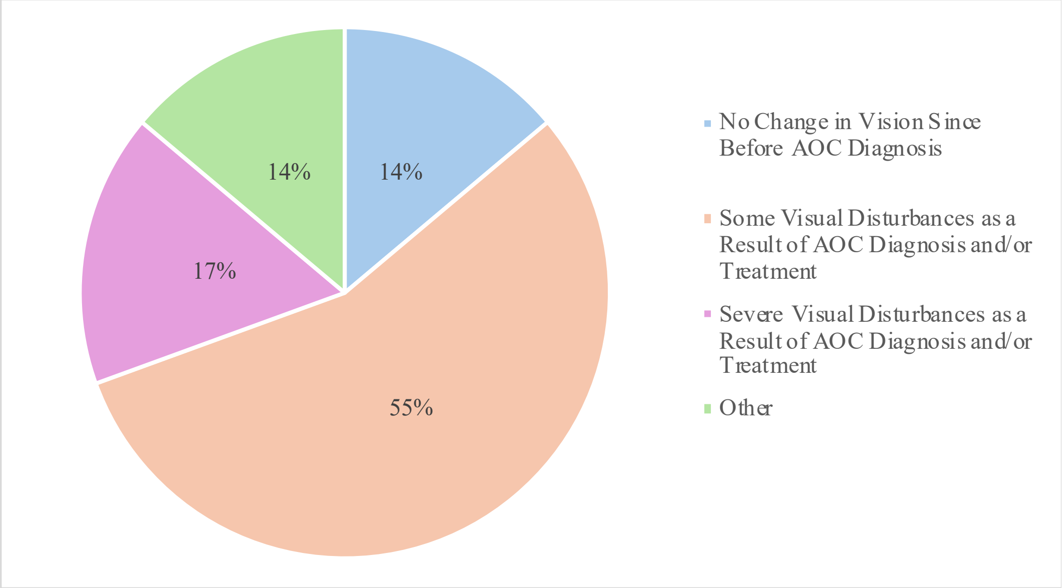
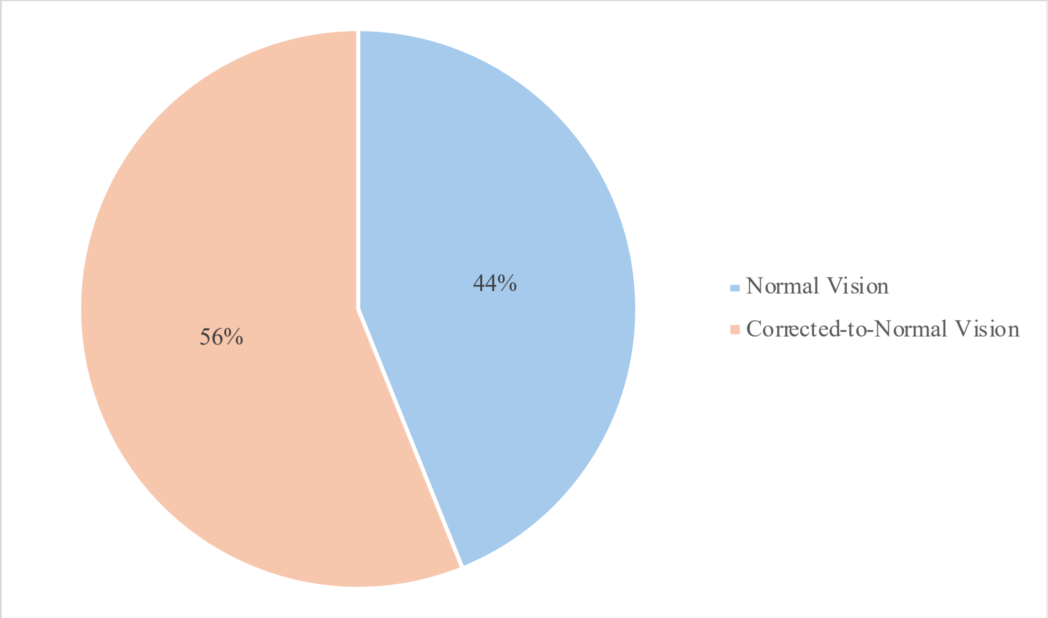


Figure 4

Vision of Controls



3.3.1.7 Diagnosed and Self-Diagnosed Mental Health. Participants with AOC and controls reported several diagnosed and self-diagnosed mental health conditions, alongside the treatment that they received. Tables 8 and 9 summarise the diagnosis and treatment of participants that provided this information. Sixteen participants with AOC and 10 controls reported a diagnosed mental health condition: some reported comorbidities. Fifteen participants with AOC and all 10 controls reported receiving treatment for their diagnosed mental health condition. Seven participants with AOC and eight controls reported a self-diagnosed mental health condition. Some participants reported receiving treatment.

Table 8

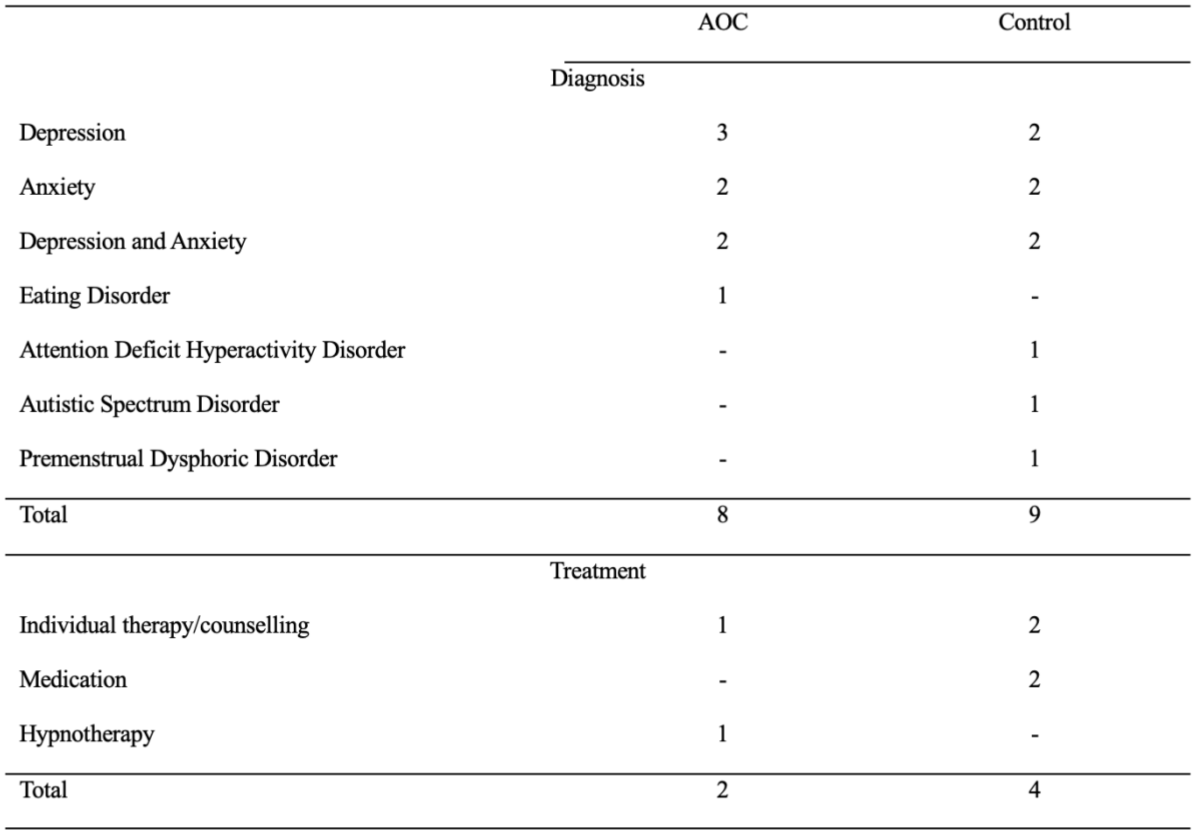
Diagnosed Mental Health Conditions and Treatment of AOC Participants and Controls

	AOC	Control
Diagnosis		
Anxiety	5	2
Depression/Low Mood	3	5
Anxiety and Depression	6	1
Obsessive Compulsive Disorder	1	-
Post-Traumatic Stress Disorder	5	-
Stress	-	1
Attention Deficit Hyperactivity Disorder	-	1
Total	20	10
Treatment		
Medication	11	9
Individual therapy/counselling/support	9	5
Group therapy	1	1
Holistic approach	-	1
Total	21	16

Note. Total number is the total number of diagnoses or methods of treatment as some participants reported multiple diagnoses and methods of treatment.

Table 9

Self-Diagnosed Mental Health Conditions and Treatment of AOC Participants and Controls



	AOC	Control
Diagnosis		
Depression	3	2
Anxiety	2	2
Depression and Anxiety	2	2
Eating Disorder	1	-
Attention Deficit Hyperactivity Disorder	-	1
Autistic Spectrum Disorder	-	1
Premenstrual Dysphoric Disorder	-	1
Total	8	9
Treatment		
Individual therapy/counselling	1	2
Medication	-	2
Hypnotherapy	1	-
Total	2	4

Note. Total number is the total number of diagnoses or methods of treatment as some participants reported multiple diagnoses and methods of treatment.

3.3.2 Distribution of Data on Each Measure

Normality was checked for the data of each measure by reviewing relevant statistics (Table 10) and visuals (histogram, Q-Q plot, box plot). For 11 of the 12 measures, a review of the statistics and visual review of the histogram and the normal quantile-quantile (QQ) plot supported the normality claim, with the histogram exhibiting a bell-shaped curve, and the QQ plot representing a close arrangement of experimental quantiles with the anticipated quantiles for a normal distribution. These conclusions together proposed that the data was approximately normally distributed for 11 measures, therefore, in subsequent analyses, parametric statistical analyses were used. Nonetheless, for one measure, the Impact of Vision

Impairment, the same conclusions could not be made with regards to a normal distribution, therefore it was concluded that data is not normally distributed and a square root transformation was used to stabilise variance in data and improve normality (Bartlett, 1936). This transformation was appropriate for use as negative values were not present and there were no values below one, except for the value of zero (Osborne, 2002).

Table 10

Normal Distribution Statistics

			Kolmogorov-Smirnov		
	Skewness	Kurtosis	Statistic	df	Sig.
Beck Depression Inventory	.611	.042	.082	77	.200
Generalised Anxiety Disorder	.597	-.639	.138	77	.001
Rosenberg Self-Esteem	-.111	.237	.076	77	.200
Toronto Alexithymia Scale	-.230	-.407	0.56	77	.200
CD-Resilience Scale	.207	.103	.082	77	.200
Emotion Regulation Cognitive Reappraisal	-.318	-.303	.092	77	.174
Emotion Regulation Expressive Suppression	-.033	-.785	.093	77	.094
Social Functioning Scale	-.519	-.101	.084	77	.200
REACT Scale	.541	-.546	.130	77	.003
Chalder Fatigue Scale	.261	-.991	.113	77	.016
Impact of Vision Impairment	.596	-.616	.215	77	<.001

3.3.3 Independent Sample T-Test or Non-Parametric Equivalent

In the pre-registration of the study, the direction of significant difference was stated, therefore, one-tailed t-test results are reported below. Eight results indicated a significant difference in the expected direction between the participants with AOC and controls. Four of the results found no significant difference between groups. The smaller-than-expected sample size should be taken into consideration when considering the reported results

3.3.3.1 Mental Health Measures. An independent samples t-test found that participants with AOC (*M* = 19.31, *SD* = 8.91) have significantly higher symptoms of depression compared to controls (*M* = 10.49, *SD* = 9.74), *t*(75) = 4.13, *p* = <.001 (Figure 5).

An independent samples t-test found that participants with AOC (*M* = 7.56, *SD* = 4.44) have significantly higher symptoms of generalised anxiety compared to controls (*M* = 5.39, *SD* = 4.72), *t*(75) = 2.07, *p* = .021 (Figure 6).

Figure 5

Participants With AOC Have Greater Depressive Symptoms Compared to Controls

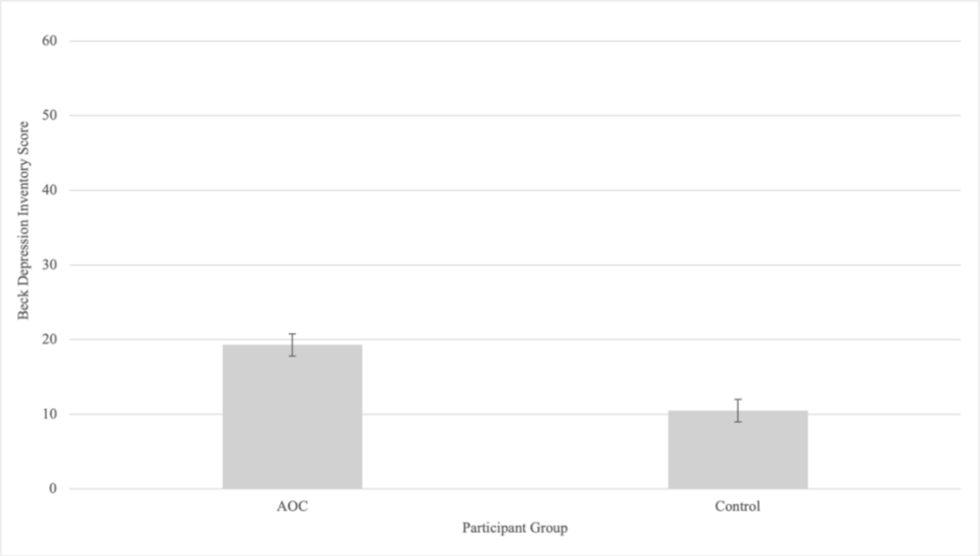
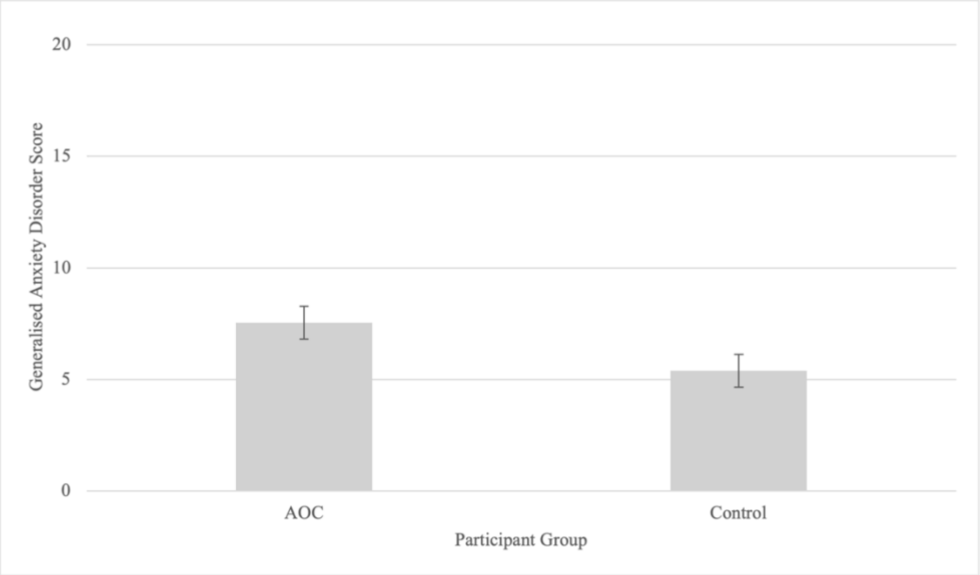


Figure 6

Participants With AOC Have Greater Symptoms of Anxiety Compared to Controls



3.3.3.2 Psychological Health Measures. An independent samples t-test found no significant difference in self-esteem scores of participants with AOC (*M* = 16.36, *SD* = 5.48) compared to controls (*M* = 17.71, *SD* = 6.22), *t*(75) = -1.00, *p* = .160 (Figure 7).

An independent samples t-test found that participants with AOC (*M* = 56.00, *SD* = 12.64) have significantly more difficulty in identifying and describing emotions compared to controls (*M* = 47.34, *SD* = 12.77), *t*(75) = 2.98, *p* = .002 (Figure 8).

An independent samples t-test found no significant difference in the use of cognitive reappraisal to emotionally regulate between participants with AOC (*M* = 27.86, *SD* = 7.12) and controls (*M* = 27.88, *SD* = 7.24), *t*(75) = -.010, *p* = .496 (Figure 9). An independent samples t-test found no significant difference in the use of expressive suppression to emotionally regulate between participants with AOC (*M* = 14.72, *SD* = 5.45) and controls (*M* = 15.17, *SD* = 5.76),), *t*(75) = -.350, *p* = .364 (Figure 10).

Figure 7

Participants With AOC and Controls Have Similar Levels of Self-Esteem

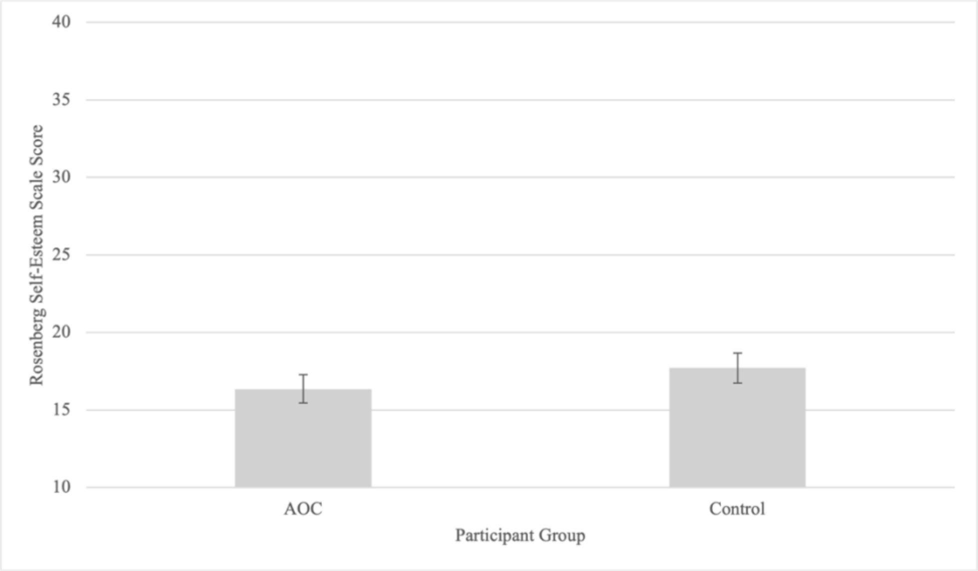


Figure 8

Participants With AOC Have Greater Difficulty in Identifying and Describing Emotions Compared to Controls

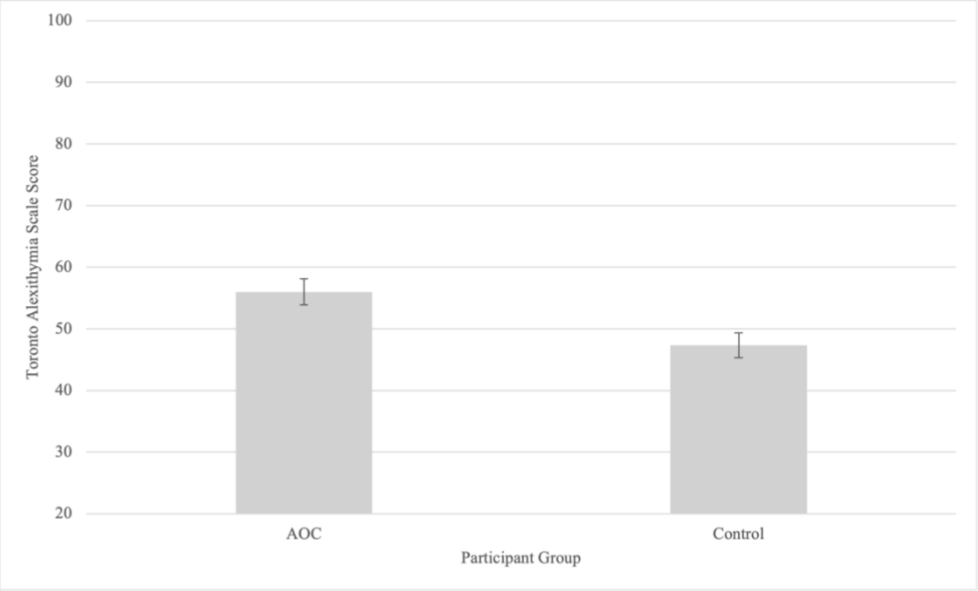


Figure 9

Participants With AOC and Controls Similarly Regulate Emotions by Cognitively Reappraising Them

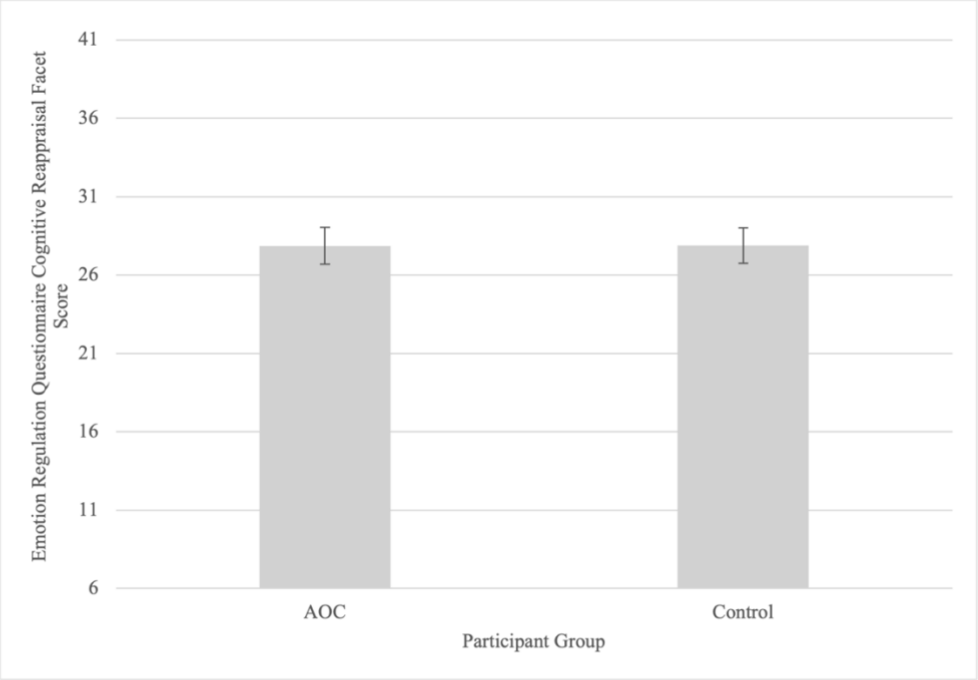
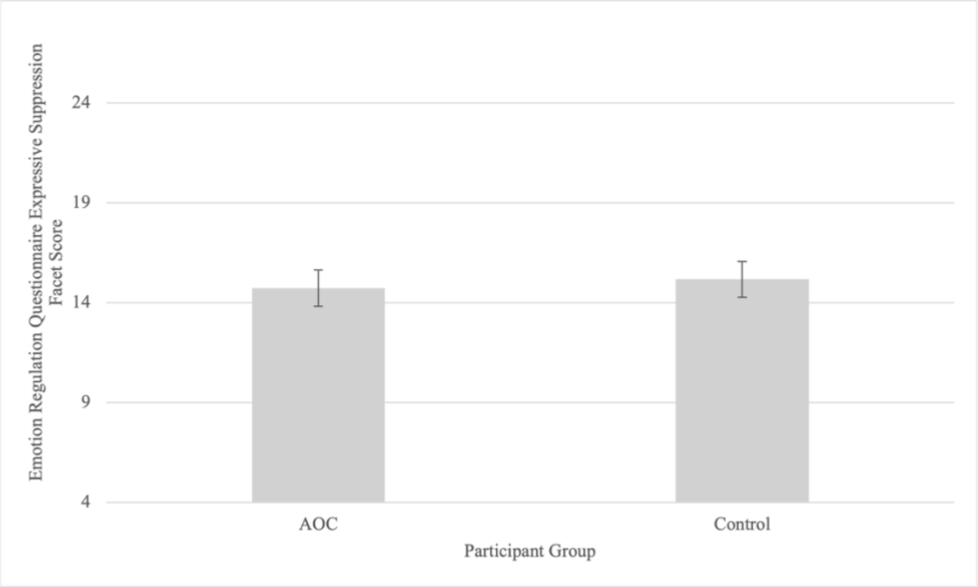


Figure 10

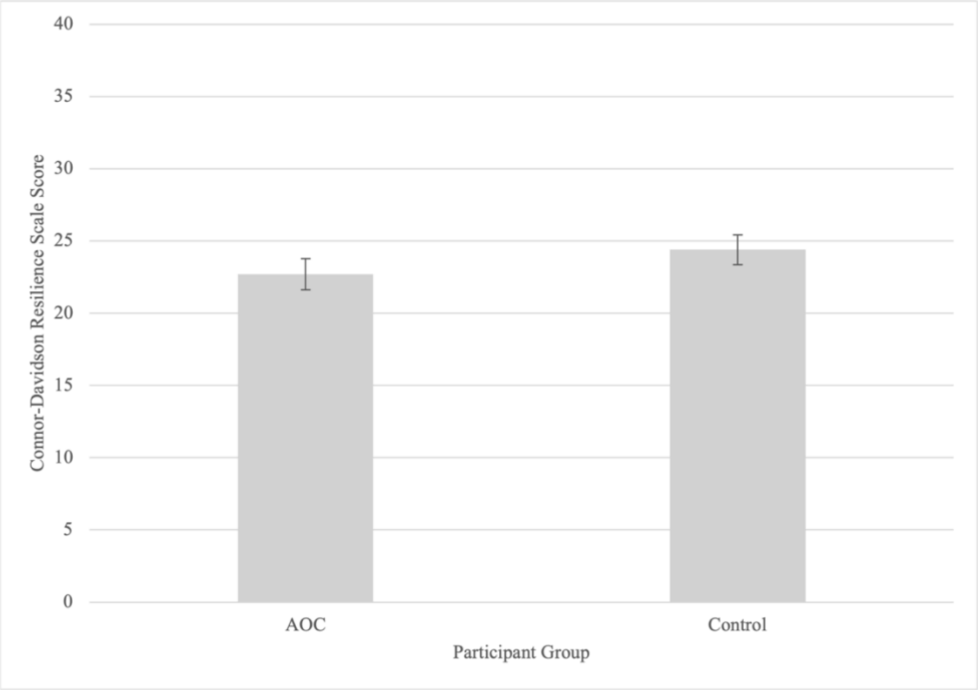
Participants With AOC and Controls Similarly Regulate Emotions by Expressively Suppressing Them



An independent samples t-test no significant difference in the resilience of participants with AOC (*M* = 22.69, *SD* = 6.42) and controls (*M* = 24.39, *SD* = 6.64), *t*(75) = -1.14, *p* = .130 (Figure 11).

Figure 11

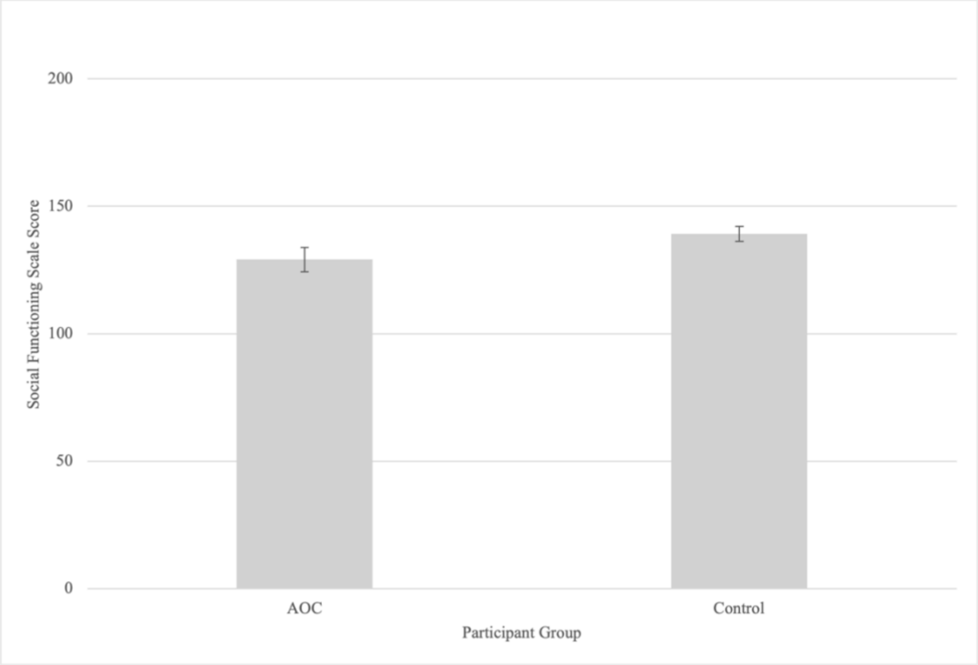
Participants With AOC and Controls Have Similar Levels of Resilience



An independent samples t-test found that participants with AOC (*M* = 129.06, *SD* = 28.82) score significantly lower on levels of social functioning compared to controls (*M* = 139.10, *SD* = 18.88), *t*(59) = -1.78, *p* = .040 (Figure 12). Levene's Test for Equality of Variances indicated significant differences in variances, *F*(1,75) = 8.24, *p* = .005, therefore the equal variances not assumed data is reported above. As Levene's Test for Equality of Variances was significant, the data for the Social Functioning Scale was subject to a square root transformation, however, the transformation moved skewness further from 0 (-.769). Therefore, the original data for this variable will be used.

Figure 12

Participants With AOC Have Lower Levels of Social Functioning Compared to Controls



3.3.3.3 Physical Health Measures. An independent samples t-test found that participants with AOC (*M* = 80.61, *SD* = 42.22) have significantly more restrictions in their lives due to how they feel about their weight, body shape or size compared to controls (*M* = 52.68, *SD* = 41.19), *t*(75) = 2.93, *p* = .002 (Figure 13).

An independent samples t-test found that participants with AOC (*M* = 22.33, *SD* = 5.93) have significantly higher levels of fatigue compared with controls (*M* = 15.24, *SD* = 5.25), *t*(75) = 5.57, *p* = <.001 (Figure 14).

For descriptive purposes, to allow interpretation of data, the original Impact of Vision Impairment Scale (Lamoureux et al., 2008) descriptive data is reported for participants with AOC (*M* = 30.58, *SD* = 23.56) and controls (*M* = 17.10, *SD* = 21.03) (Figure 15). An independent samples t-test performed on the square root transformed data found that participants with AOC (*M* = 4.77, *SD* = 2.84) have significantly more interferences and concerns in their lives due to vision impairment compared to controls (*M* = 3.04, *SD* = 2.84), *t*(75) = 2.67, *p* = .005.

Figure 13

Participants With AOC Have More Restrictions in Their Lives due to how They Feel About Their Weight, Body, Shape or Size Compared to Controls

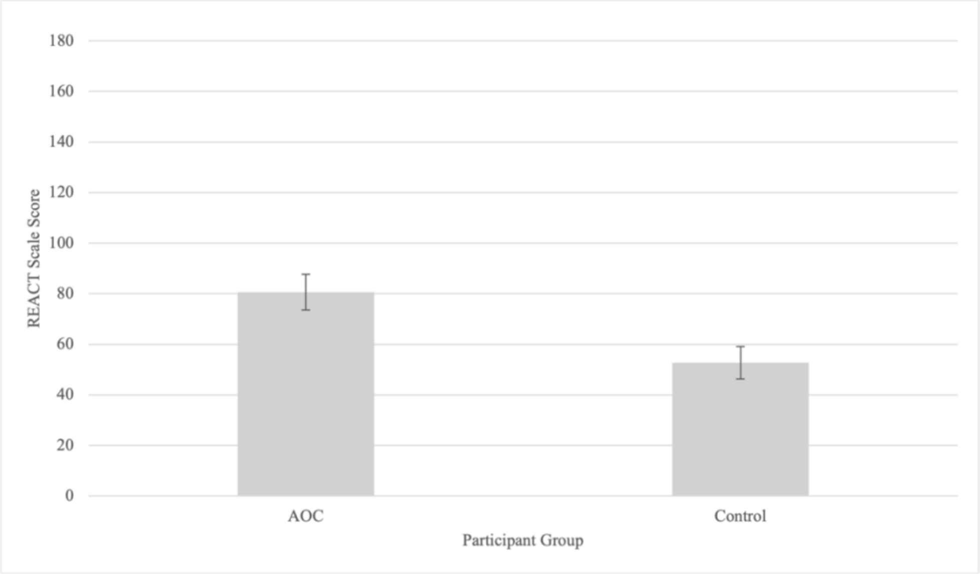


Figure 14

Participants with AOC Have Higher Levels of Fatigue Compared to Controls

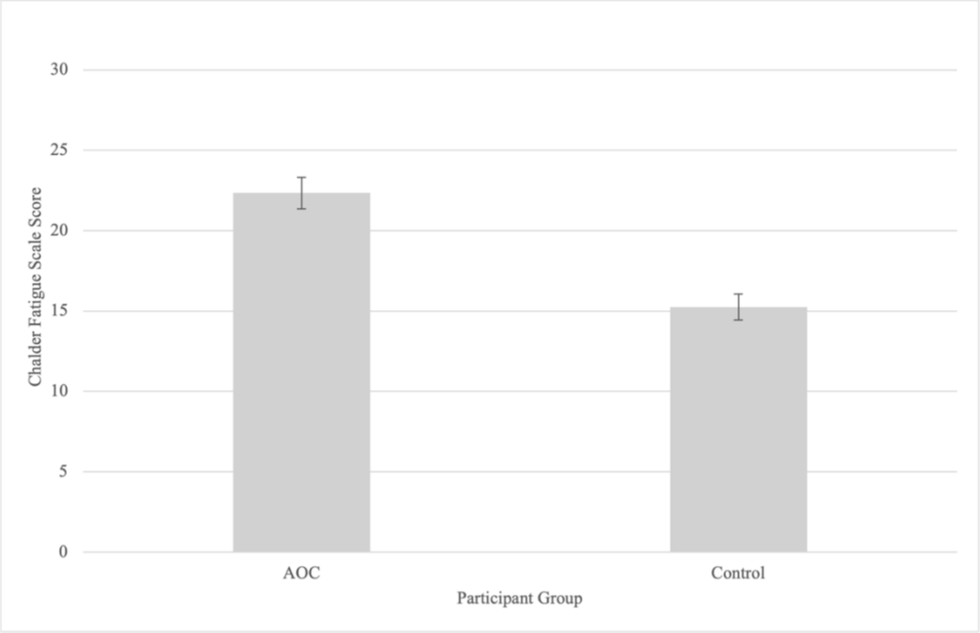
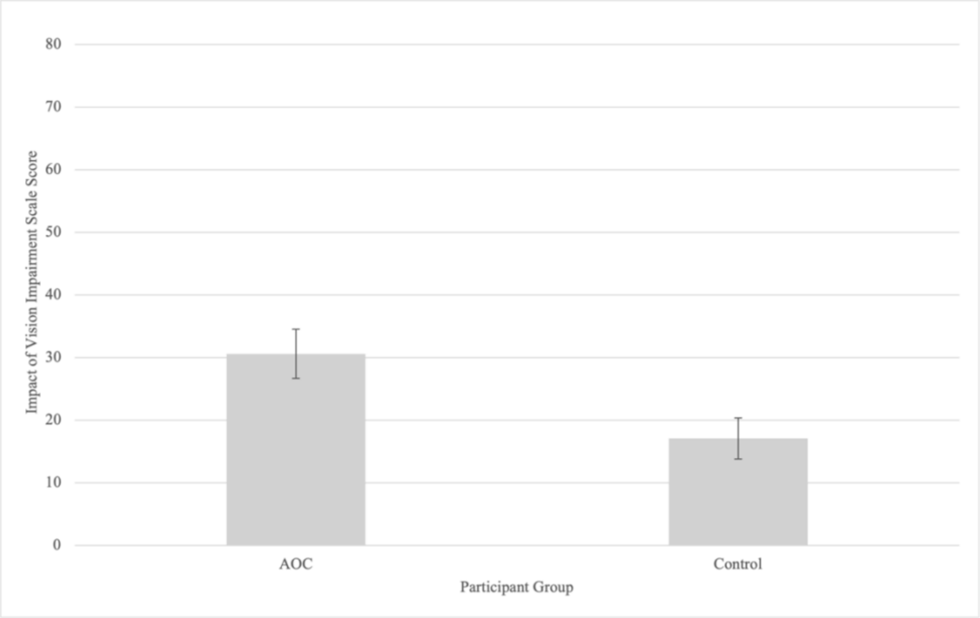


Figure 15

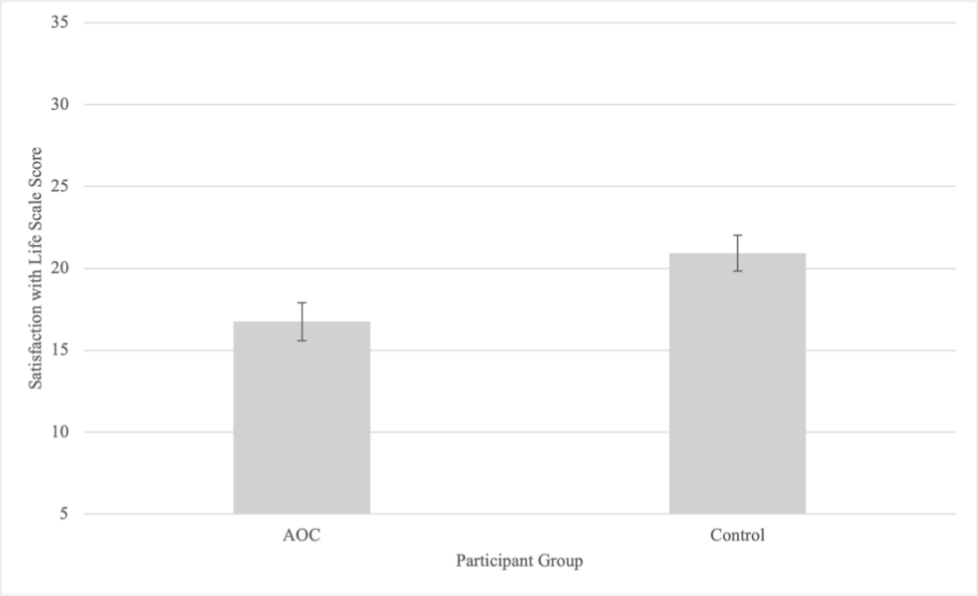
Participants with AOC Have More Difficulties in Life as a Result of Vision Impairment Compared to Controls



3.4.4.4 Satisfaction with Life Scale. An independent samples t-test found that participants with AOC (*M* = 16.75, *SD* = 6.97) have significantly lower satisfaction with their lives compared to controls (*M* = 20.93, *SD* = 6.97), *t*(75) = -2.62, *p* = .005 (Figure 16).

Figure 16

Participants with AOC Have Less Satisfaction with Life Compared to Controls



3.3.4 Multiple Linear Regression Analysis

The multiple linear regression analysis aimed to determine whether psychological health outcomes are predictors of satisfaction with life in participants with AOC. Additionally, the analysis also aimed to determine whether physical health outcomes are predictors of satisfaction with life in participants with AOC.

3.3.4.1 Psychological Health Measures. Multiple linear regression revealed that the psychological health variables significantly predicted satisfaction with life scores in AOC participants ($F(8, 27) = 4.82$, $p = <.001$), explaining 58.8% of variance ($R^2 = 0.588$). Participants' self-esteem ($t = 2.331$, $p = .027$) and anxiety ($t = 2.062$, $p = .049$) scores significantly predicted greater life satisfaction, while participants' depression ($t = -2.028$, $p = .052$) scores trended towards significantly lower life satisfaction (Table 11). The remaining variables did not significantly predict life satisfaction.

Table 11

Multiple Regression Coefficients: Satisfaction With Life as Outcome Variable, and Psychological Health Measures as Predictors

	B	SE B	β	t	Sig.	VIF
Constant	-2.236	11.833		-.189	.852	
Beck Depression Inventory	-.386	.190	-.493	-2.028	.052	3.877
Generalised Anxiety Disorder	.589	.286	.375	2.062	.049	2.166
Rosenberg Self-Esteem	.644	.276	.506	2.331	.027	3.090
Toronto Alexithymia Scale	.067	.142	.122	.473	.640	4.322
CD-Resilience Scale	.026	.178	.024	.144	.886	1.752
Emotion Regulation Cognitive Reappraisal	.275	.147	.281	1.874	.072	1.478
Emotion Regulation Expressive Suppression	.033	.221	.026	.151	.881	1.952
Social Functioning Scale	-.008	.038	-.033	-.214	.832	1.607

Note. B = Unstandardised Coefficients, SE B = Standard Error of Unstandardised Coefficients, β = Standardised Coefficients Beta, t = t-statistic, VIF = Variation Inflation Factor

The Durbin-Watson statistic was calculated as 1.622, indicating no significant autocorrelation among the residuals. The Variation Inflation Factor (VIF) score was under 5 for all variables, and therefore all variables were kept in the analysis. Furthermore, no outliers were indicated within the Standardised Residuals, the minimum and maximum cut off are -3.29 and 3.29 (Field, 2013), and all scores fell within this range. The normal P-P Plot of Regression Standardised Residual indicated a normal distribution, likewise, the histogram indicated a normal distribution. Therefore, the data meets the assumption for regression analysis and transformation was not required.

3.3.4.2 Physical Health Measures. Multiple linear regression revealed that the physical health variables[11] significantly predicted satisfaction with life scores in AOC

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[11] As the Impact of Vision Impairment Scale data did not meet the assumption of normality, the regression was run with the square root transformation data. All other variables data was the original normally distributed data.

participants (*F*(3, 32) = 3.87, *p* = .018.), explaining 26.6% of the variance ($R^2 = 0.266$). Participants' fatigue score (*t* = -2.619, *p* = 0.13) significantly predicted lower life satisfaction (Table 12). The remaining variables did not significantly predict life satisfaction.

Table 12

Multiple Regression Coefficients: Satisfaction With Life as Outcome Variable, and Physical Health Measures as Predictors

	B	SE B	β	t	Sig.	VIF
Constant	30.593	4.216		7.257	<.001	
REACT Scale	-.013	.026	-.079	-.494	.625	1.106
Chalder Fatigue Scale	-.519	.198	-.441	-2.619	.013	1.237
Impact of Vision Impairment Scale	-.252	.396	-.103	-.638	.528	1.135

Note. B = Unstandardised Coefficients, SE B = Standard Error of Unstandardised Coefficients, β = Standardised Coefficients Beta, t = t-statistic, VIF = Variation Inflation Factor

The Durbin-Watson statistic was calculated as 1.992, indicating no significant autocorrelation among the residuals. The Variation Inflation Factor (VIF) score was under 5 for all variables, and therefore all variables were kept in the analysis. Furthermore, no outliers were indicated within the Standardised Residuals, the minimum and maximum cut off are -3.29 and 3.29 (Field, 2013), and all scores fell within this range. The normal P-P Plot of Regression Standardised Residual indicated a normal distribution, likewise, the histogram indicated a normal distribution. Therefore, the data meets the assumption for regression analysis and transformation was not required.

3.4 Study Two

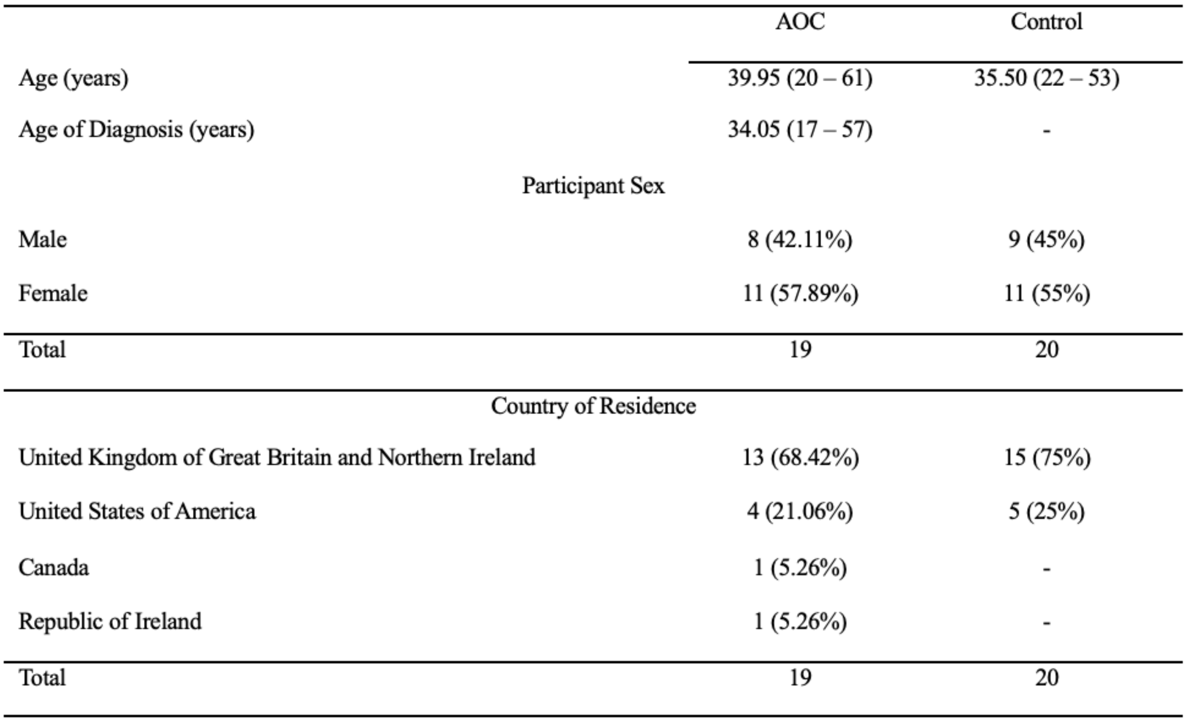
3.4.1 Demographics and Participant Characteristics

3.4.1.1 Age and Sex. Participants with AOC had a mean age of 39.95 years and controls had a mean age of 35.50 years (Table 13). One participant included was diagnosed with COC. An independent samples t-test confirmed that there was no significant difference in age of the participants with AOC (M = 39.95, SD = 10.47) and controls (M = 34.50, SD = 9.75), $t(37) = 1.68$, $p = .101$. Of all the participants, over 50% were female. A chi-square test of independence confirmed there was no significant difference in sex distribution across groups, $\chi^2(1, N = 39) = 0.33$, $p = .855$.

3.4.1.2 Country of Residence. Of the participants with AOC (n = 19), the majority (89%) were from the United Kingdom of Great Britain Northern Ireland and the United States of America (Table 13). Of the controls (n = 20), all participants were from the United Kingdom of Great Britain and Northern Ireland or the United States of America.

Table 13

Study Two Participant Demographics



	AOC	Control
Age (years)	39.95 (20 – 61)	35.50 (22 – 53)
Age of Diagnosis (years)	34.05 (17 – 57)	-
Participant Sex		
Male	8 (42.11%)	9 (45%)
Female	11 (57.89%)	11 (55%)
Total	19	20
Country of Residence		
United Kingdom of Great Britain and Northern Ireland	13 (68.42%)	15 (75%)
United States of America	4 (21.06%)	5 (25%)
Canada	1 (5.26%)	-
Republic of Ireland	1 (5.26%)	-
Total	19	20

3.4.1.3 Mental and Physical Health. Five participants with AOC reported diagnosed mental health disorders and all five accessed treatment. Two additional participants with AOC reported self-diagnosed mental health disorders and one accessed treatment. In Table 14 the physical health of participants with AOC is summarised. This data is revised from the data collected in Study One as this data was not collected again during Study Two and is presented just for interest purposes (therefore there is no data for controls). Figure 17 shows the visual functioning of participants with AOC.

Table 14

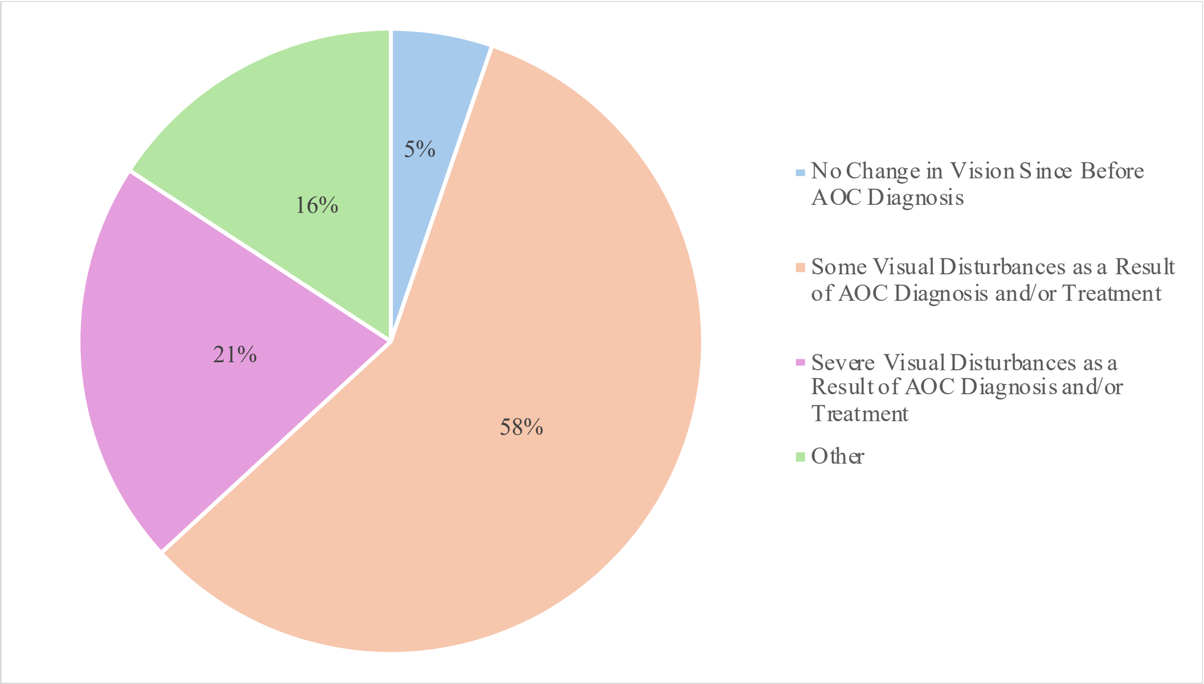
Study Two Participants with AOC Physical Health (Revised From Study One)

		AOC
Height	Male	5’ 5” (5’ 2” – 5’ 9”)
	Female	5’ 6” (5’ 1” – 5’ 11”)
Weight		12st 7lb (8st 2lb – 16st 5lb)
Surgery		19 (100%)
Radiotherapy		11 (57.90%)
Diabetes Insipidus		9 (47.37%)
Hormone Replacement Therapy		13 (68.42%)
Growth Hormone		4 (21.05%)

Note. ‘ = feet, “ = inches, st = stone, lb = pounds

Figure 17

Vision of AOC Participants (Revised From Study One)



3.4.2 Categories Included for Analysis

In the pre-registration, there were 15 categories identified (see Methods Chapter pp. 72) to be explored to address the primary research question. Because LIWC analyses participants' written responses to a free textbox, the data obtained is dependent on the content of the responses, therefore for some participant responses, the LIWC dictionary did not generate a score as words captured under the category were not identified. Therefore, if the value was 0, this was classed as missing data. It was decided that for a category to be included in the analysis, it must have less than 50% missing data meaning that LIWC had to have generated a score for at least 15 of the 30 videos analysed. This rule resulted in 6 categories being excluded from the analysis (a) negative tone (b) negative emotion (c) anxious emotion (d) angry emotion (e) sad emotion (f) feeling. Because negative tone and negative emotion were excluded, positive tone and positive emotion categories were also excluded due to lack of comparison. Consequently, the analysis was conducted on the overall category of Tone and Emotion. Ultimately, eight categories were excluded and seven were included in the analysis. Additionally, word count data was included.

3.4.3 Distribution of Data on Each Category and Word Count

For all categories, a review of the statistics (Table 15) and a visual review of the histogram and Q-Q plot led to the conclusion that the data was not normally distributed, and in subsequent analyses, non-parametric statistical analyses were used. Table 16 summarises the descriptive statistics for the categories.

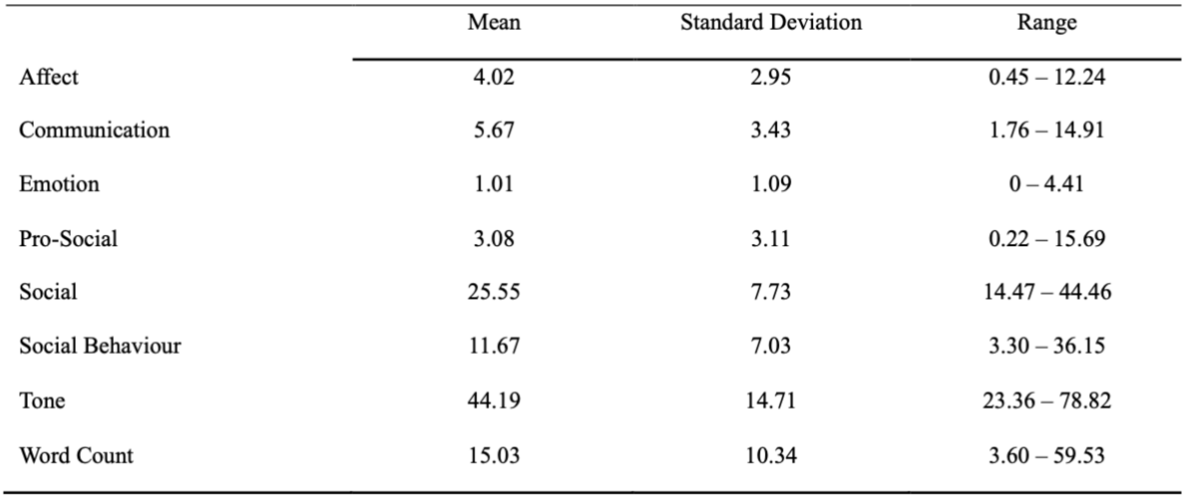
Table 15

Normal Distribution Statistics

			Kolmogorov-Smirnov		
	Skewness	Kurtosis	Statistic	df	Sig.
Affect	.854	.113	.131	39	.090
Communication	1.110	.233	.224	39	<.001
Emotion	1.183	1.128	.176	39	.004
Pro-Social	1.972	5.823	.179	39	.003
Social	.950	.280	.173	39	.005
Social Behaviour	1.348	2.308	.201	39	<.001
Tone	.721	-.290	.121	39	.155
Word Count	2.23	7.90	.134	39	.073

Table 16

Study Two Category Descriptives



	Mean	Standard Deviation	Range
Affect	4.02	2.95	0.45 – 12.24
Communication	5.67	3.43	1.76 – 14.91
Emotion	1.01	1.09	0 – 4.41
Pro-Social	3.08	3.11	0.22 – 15.69
Social	25.55	7.73	14.47 – 44.46
Social Behaviour	11.67	7.03	3.30 – 36.15
Tone	44.19	14.71	23.36 – 78.82
Word Count	15.03	10.34	3.60 – 59.53

3.4.4 Mann-Whitney U Test

As all variables were deemed not normally distributed, Mann-Whitney U Tests were performed. These showed no significant difference between the mean of the LIWC-generated scores for participants with AOC and controls in any of the categories included for analysis (see Table 17 for all analyses).

Table 17

Mann-Whitney U Test Data

	Mann-Whitney U	P-Value	Mean Rank	
			AOC	Control
Affect	150.00	.270	22.11	18.00
Communication	173.00	.647	20.89	19.15
Emotion	204.50	.687	19.24	20.73
Pro-Social	141.00	.175	22.58	17.55
Social	158.00	.380	21.68	18.40
Social Behaviour	126.00	.074	23.37	16.80
Tone	158.50	.380	21.66	18.43
Word Count	236.00	.204	17.58	22.30

3.5 Chapter Summary

In summary, participants with AOC demonstrated significantly more depressive and anxious symptoms, greater alexithymia, poorer social functioning, greater disruption related to their body size, greater fatigue and more impact as a result of their vision compared to controls. Additionally, participants with AOC had significantly lower satisfaction with life compared to controls. Finally, for Study One, participants' depression, anxiety, resilience and fatigue scores predicted their satisfaction with life. In Study Two, no significant differences were found between written responses to social interactions for participants with AOC and controls. However, with all results reported from both studies, it is important to consider the smaller-than-expected sample size.

Chapter Four: Discussion

4.1 Chapter Summary

Within this chapter, the results of the current studies will be summarised, and interpretations of the results will be made. Afterwards, the strengths and limitations will be considered. Then, the implications of the current studies concerning practice, theory and future research will be discussed. Lastly, a reflexive statement from the researcher will be presented.

4.2 Overview of The Studies

The present studies used a quantitative approach to provide an original understanding of the psychological impact of AOC. In the first study, the psychological impact was measured using a battery of gold-standard questionnaires. Independent Samples T-Tests or their non-parametric equivalents examined differences between participants with AOC and controls in their scores for the various measures to understand where significant difficulties may lie. Following this, two multiple linear regression models for the psychological and physical health variables for the participants with AOC were conducted to understand which measures, if any, significantly predicted a poorer quality of life.

In the second study, participants with AOC social and emotional functioning were considered through their written responses to viewing social interactions, these results were compared with matched controls. Mann-Whitney U Tests were run to examine differences in various social and emotional categories. The present studies addressed two main research aims.

4.3 Research Hypotheses

All research hypotheses were rejected due to the studies not being appropriately powered; however, it is noted that some of the results found in Study One may support the hypotheses. In Study One, despite the findings supporting the first research hypothesis in that participants with AOC scored significantly higher on measures of mental health disorders compared to controls, the hypothesis was rejected due to the study being underpowered. The second research hypothesis was rejected. The results partially supported the second research hypothesis, that participants with AOC would score significantly lower on self-esteem, understanding feelings, emotion regulation, resilience and social functioning compared to controls. This is due to within this hypothesis, there was a significant difference for two of the five measures (a) Toronto Alexithymia Scale (b) Social Functioning Scale. The third research hypothesis was rejected; however, participants with AOC scored significantly higher in measures of physical health difficulty and significantly lower in general satisfaction with life. Finally, the findings supported the fourth research hypothesis in that the psychological well-being and physical health of participants with AOC significantly predicted satisfaction with life, however this research hypothesis was also rejected due to underpower. In Study Two, the research hypothesis was rejected. No significant differences were found in social and emotional content between the groups when rating videos of social interactions.

4.4 Interpretation of Study One Results

The interpretation of all results from Study One should be done whilst holding in mind that the sample size was smaller than expected, which may have compromised the study's statistical power.

4.4.1 Mental Health Measures

4.4.1.1 Beck Depression Inventory. The results indicated participants with AOC had significantly higher symptoms of depression than controls. This suggests that a diagnosis of AOC is associated with higher levels of depression than in controls. This supports the pre-existing literature finding that participants with craniopharyngioma score significantly higher than controls for symptoms of depression (Roemmler-Zehrer et al., 2015) and in participants with AOC there is both pre-and post-operative depression or "slowing down" (Apra et al., 2019; Zhao et al., 2021). Furthermore, the present findings support Daughters et al (2023) as participants with AOC and clinicians both identified common difficulties associated with AOC being "low moods" and participants recognised themselves as being "borderline depressed". Conversely, Honegger et al (1998) found that only one participant with AOC identified as being depressed and Dekkers et al (2006) found no significant difference in depression scores between participants with AOC and volunteers. These findings in contrast with the present research are less recent and may indicate a time when there was less focus and understanding of depression.

This present research finding can support the understanding that participants with AOC have depressive symptoms to a greater extent than controls. The findings of the present study are not only picking up typical levels of depression within the general population, however, they may also highlight that participants with AOC could be at greater risk of depression than the general population. This therefore provides a specific intervention point for patients with AOC that could improve their overall sense of well-being.

This significant finding can be understood in the context of the three domains of the Biopsychosocial Model discussed in Chapter One (pp. 17-18). The Biopsychosocial Model is interested in the interaction of biological, psychological and social factors and the subsequent impact of this interaction on the individual (Suls & Rothman, 2004). Firstly, the biological factors that might be impacting low mood for a patient with AOC include hormonal imbalances, physical impacts of surgery and radiation, and fatigue. Secondly, the psychological factors include low mood as a result of diagnosis of a chronic illness, reduced independence and ability to carry out activities of daily living. Lastly, the social factors may be a change in relationships as a result of symptoms of AOC, such as changes in ability to work, potential increase in financial stress and increased time spent in medical settings. One domain cannot solely explain the depressive symptoms, instead, there is a complex interplay between the factors. The biological impact of the course and outcome of AOC can be understood to be deeply impacted by psychological and social factors (Havelka et al., 2009).

Furthermore, following treatment, a patient with AOC may experience various concerns. These concerns may include tumour recurrence, long-term health outcomes and fear of reduced life expectancy. Without access to the right mental health support, these anxieties could lead to cycles of rumination and low mood. The cycles of depressive symptoms can be understood with the use of Cognitive Behavioural Therapy (Beck, 2020). The Cognitive Behavioural Therapy cycle considers thoughts, feelings, behaviours and physical sensations. This cycle of low mood can be applied to a patient with AOC as the patient with AOC may have the thought “I can’t function in the same way that I used to, I’m so useless”. This thought might lead to the patient feeling sad and angry and therefore isolating themselves by cancelling social activities that they had planned with family and friends. Physically the patient might feel their body is achy and that they are fatigued. These four factors of the cycle could result in the patient with AOC’s negative thoughts and beliefs about themselves and their life being reinforced repeatedly (Hawley et al., 2017). If the cycle is not interrupted, this could lead to an overall reduction in positive experiences and perpetuation of their difficulties. Behavioural activation strategies are introduced at the initial stage of treatment with the use of CBT (Martell et al., 2001), this assists the patient to observe the relationship between their behaviours and other parts of the cycle. This can help alleviate symptoms by engaging in adaptive behaviours. Therefore, psychological therapeutic support would be necessary for patients with AOC to break the cycle and help reframe thoughts, increase engagement in manageable and meaningful activity and improve certain areas of physical well-being. Improved outcomes for patients with Coronary Heart Disease and Chronic Pain have been found with the use of Cognitive Behavioural Therapy (Dong et al., 2023; Sanabria-Mazo et al., 2023). The offering of Cognitive Behavioural Therapy to patients with AOC may contribute to improved psychological and physical health outcomes.

4.4.1.2 Generalised Anxiety Disorder. The findings of the present research demonstrated that participants with AOC scored significantly higher on symptoms of anxiety compared with controls. This suggests that a diagnosis of AOC is associated with higher levels of anxiety. The findings of the present research support existing literature as participants with AOC have previously been found to score significantly higher than controls on measures of anxiety (Roemmler-Zehrer et al., 2015) and anxiety has been identified as a core psychological symptom by both clinicians and participants with AOC (Daughters et al., 2023). Further existing literature reported anxiety in participants with AOC (Zhao et al., 2021) and on the Distress Thermometer participants with AOC most frequently identified the category “worry” as an area they were experiencing psychological distress (Lucia et al., 2024). In contrast to the above literature, Dekkers et al (2006) found no significant differences in anxiety between participants with AOC and volunteers.

The present research findings of increased anxiety in participants with AOC might be understood with reference to the rare nature of AOC. Patients may feel alone in managing the diagnosis and treatment, which could increase anxiety levels. Previous literature has detailed that chronic conditions were positively associated with anxiety (El-Gabalawy et al., 2011). Patients with AOC may not feel able to seek support from their usual support network, which may lead to increased levels of anxiety and coping alone. The Cognitive Behavioural Therapy cycle explained in relation to depression above can also be applied to the experience of anxiety (Loerinc et al., 2015). Patients with AOC may get stuck in cycles of anxiety and overthinking. The patient with AOC may struggle to break this cycle of anxiety and require psychological support to cope with and manage debilitating anxiety levels. Previous research has found CBT is associated with improved outcomes with regard to anxiety (Van Dis et al., 2020).

Due to the chronic nature of AOC, patients with AOC may experience heightened health anxiety. This health anxiety may be longstanding and could impact on quality of life (Lebel et al., 2020). The nature of the chronic illness results in regular medical appointments for patients, this in turn leads to a focus on health and symptoms. Over time, patients with AOC may come to seek reassurance from medical professionals with regard to their symptoms. Patients with AOC will be tuned into paying attention to feelings and sensations in their bodies and have the potential to attribute normal feelings and sensations as catastrophic and problematic, due to negative experiences with health, leading to a cycle of anxiety. However, some fears and concerns experienced by patients with AOC will be classed as normal, and these need to be distinguished from clinical anxieties (Lebel et al., 2020).

Furthermore, patients with AOC may experience anxiety due to the uncontrollable change that comes with being diagnosed with a brain tumour. Previous research has found that there is a high incidence of anxiety among patients with chronic disease (Swathi et al., 2023). Often, patients with AOC experience a range of symptoms prior to seeking medical support, despite this, diagnosis may come as a shock. The nature of a diagnosis of a brain tumour can lead to many changes in various areas of life, potentially leading to a sense of loss of control for patients with AOC. An approach to consider supporting patients with AOC's anxiety and distress could be Acceptance and Commitment Therapy (Harris, 2006). This approach is an evidence-based therapy commonly used to treat anxiety and depression (Annunziata et al., 2016). Acceptance and Commitment Therapy utilises mindfulness strategies and acceptance to move towards living a life aligned with one's values (Strosahl, 2002). Previous research found that when Acceptance and Commitment Therapy was applied to adults with primary brain tumours 75% of participants no longer met the criteria for anxiety and/or depressive disorders (Kangas et al., 2015). This finding, whilst not in patients with AOC, could shed light on the positive implications that the use of Acceptance and Commitment Therapy may have with patients with AOC who experience anxiety.

Lastly, the Uncertainty in Illness Theory (Mishel, 1988) could be helpful in explaining the experience of anxiety in participants with AOC. We can understand chronic illness, such as AOC, to foster uncertainty and unpredictability. This may contribute to anxiety due to the sense of a lack of control or ability to plan for the future with the unknown of the illness. Overall, there appear to be many different reasons and understandings of why a participant with AOC may experience more than average anxiety, supporting the need for psychological intervention to manage anxiety symptoms.

4.4.2 Psychological Health Measures

4.4.2.1 Rosenberg Self-Esteem Scale. The results of the present study indicated that there was no significant difference between participants with AOC and controls in their self-esteem scores. This differs from the previous findings of Daughters et al (2023) which found that participants signified that their self-esteem was impacted by a diagnosis of AOC with one participant reporting “I don’t like myself very much”. Furthermore, cognitive dysfunction and weight gain were also understood to negatively impact the self-esteem of participants with AOC, clinicians also agreed that they acknowledged this whilst treating patients with AOC. However, to the best of the researcher’s knowledge, this is the only paper to have investigated self-esteem in patients with AOC and utilised a qualitative approach, in contrast to the quantitative design of the present study. Therefore, further research into the self-esteem of patients with AOC is required before concluding one way or the other. Previous research has identified that chronically ill individuals can experience low self-esteem (Bedrov & Bulaj, 2018) as a result of their condition. Low self-esteem can also become an obstruction to effective management and coping with the condition.

The findings of the present research were not expected; however, the present results can be considered alongside the understanding that self-esteem is influenced by a variety of factors, including early life experiences, and secure attachment in childhood is associated with improved self-esteem (Mikulincer et al., 2009). Therefore, if a patient with AOC has had positive early life experiences, prior to diagnosis, that have led to the development of high levels of self-esteem, they may be able to draw on this experience to maintain their self-esteem, despite the difficulties associated with a diagnosis of AOC later in life. Furthermore, achievements and success throughout life can build on the human's base of high self-esteem, for example, research has found individuals that have positive social relationships have a positive influence on an individual's self-esteem (Harris & Orth, 2020), this has been described as a reciprocal relationship. Therefore, the experiences that an individual has prior to diagnosis can be understood to be fundamental in their impact on self-esteem, and high self-esteem may help the patient with AOC to stay grounded there. This understanding of self-esteem in AOC could lead to questioning whether low self-esteem is more prominent in COC and future research could explore this.

Moreover, given the present research noted significant differences with regards to participants with AOC symptoms of depression and anxiety, a significant difference would also be expected with regards to the level of self-esteem as these mood states can negatively impact self-esteem (Hawley et al., 2017). Experiences of depression and anxiety commonly involve self-criticism and negative perception of the self, and therefore this would be thought to impact self-esteem. Further exploration of self-esteem in future research would be beneficial with the use of a longer questionnaire than used in the present study. For example, the present study utilised a well-validated, but short questionnaire which may have not captured important factors of self-esteem previously identified by Daughters et al (2023).

4.4.2.2 Toronto Alexithymia Scale. The findings of the present research indicate that participants with AOC scored significantly higher on difficulty identifying feelings, describing feelings and externally oriented thinking than controls. This suggests that a diagnosis of AOC is associated with higher levels of alexithymia, which includes more difficulty in identifying own feelings, describing own feelings and thinking in an externally oriented way. This finding supports previous qualitative literature as participants with AOC reported that they struggle to identify their own feelings (Daughters et al., 2023).

The researchers propose that this significant difference may be connected to the location of craniopharyngiomas, and the subsequent disruption of pituitary gland functioning resulting in reduced oxytocin production (Daubenbüchel et al., 2016; Daughters et al., 2017), which in turn impacts emotional functioning (Hubble et al., 2017). While this body of literature has focused on the direct impact of oxytocin on recognising other’s emotions and empathy, there is a strong correlation between one’s ability to empathise and interpret one’s own emotion (Bird & Viding, 2014), thus the reduction in the production of oxytocin may also relate to alexithymia. This finding highlights the importance of oxytocin and the theoretical basis of the present thesis explored in section 1.2.8.

Alternatively, greater alexithymia in participants with AOC may be due to other hormonal imbalances, such as cortisol and oestrogen as a result of the location of the AOC tumour or the associated treatment (Zhou et al., 2021). Research has identified that there is a complex relationship between emotional regulation and hormonal fluctuations (Yılmazer, 2024). Hormone deficits in cortisol have been found in participants with craniopharyngioma following radiotherapy (Kawamata et al., 2010) and Pereira et al (2005) emphasised the importance of ensuring appropriate endocrine replacement, particularly of oestrogen for females that are premenopausal. It is possible that these imbalances may be impacting emotional functioning, and therefore a greater rate of alexithymia in AOC.

Previous research conducted by Kauhanen et al (1993) suggested that alexithymia could be viewed partly as a socially determined phenomenon, as men who scored highly for alexithymia in the study, were often unmarried with low levels of social connections and relations. As explained in Chapter One, the Biopsychosocial Model (pp. 17-18) explores the social implications of a diagnosis of AOC, which can be vast, with a large impact on the patient with AOC's social life. Furthermore, considering the present significant differences found, the importance of the theoretical basis can be acknowledged, as oxytocin plays a role in social bonds (Carter et al., 2009) and therefore the oxytocin deficiency in patients with AOC (Castle-Kirszbaum et al., 2022; Daughters et al., 2017) may be a factor to consider with regards to alexithymia.

Additionally, it might be considered that the high levels of fatigue experienced by participants with AOC may impact the ability of participants to identify and describe their feelings and emotions. For an individual who is experiencing severe fatigue, the act of paying attention to and labelling one's own emotions may feel too mentally challenging. Also, patients with AOC may have coped with overwhelming amounts of emotional pain and have, therefore, learnt to suppress emotion, resulting in emotional blunting. This can be understood with consideration of the significant difference found in depressive symptoms, as emotional blunting has been found in nearly half of depressed patients taking antidepressants (Goodwin et al., 2017). Whilst this may serve a protective function for the patient with AOC at the time, this can be seen as a maladaptive coping strategy in the longer term. Therefore, it may be that psychological intervention could support patients with AOC to understand and explore their emotional experiences.

4.4.2.3 Emotion Regulation Questionnaire. The present study results indicated that participants with AOC did not score significantly differently on emotion regulation when compared with controls. Whilst the mean score of participants with AOC was lower, this was not significant when compared to controls. A significant difference was expected as the research conducted by Daughters et al (2023) highlighted emotion regulation as a difficulty. Firstly, participants with AOC recognised themselves as being “very emotional” and “struggling to regulate their emotions”, noting this is a change since their diagnosis. Secondly, this research did not only pick up on participants with AOC experiences, but also clinicians working with AOC, and they noted emotion regulation difficulties in the patients they have treated and worked with. Therefore, given these qualitative findings, the researchers expected this to be an area of significant difference. The present research findings contrast with further research findings highlighting complaints following surgery commonly included emotion dysregulation, the impact of AOC and associated treatment lead to concerns in the emotional quality of a patient’s life and a need has been identified for emotional support following AOC intervention (Castle-Kirszbaum et al., 2022; Mende et al., 2020; Patel et al., 2015).

The findings of the present study mirror what has been seen in some previous literature as no significant difference was found between participants with AOC and controls in measures of emotion (Dekkers et al., 2006) and in an emotional component of a measure, no significant differences were found between participants with AOC and healthy controls (Pickering et al., 2014). Moreover, the COC literature has sought to explain difficulties with emotion regulation as it has been identified that 40% of participants with COC experienced emotional dysfunction, characterised by mood swings and emotional dysregulation (Zada et al., 2013). Also, Janss et al (2019) drew attention to the manifestation of psychiatric disorders in impaired emotional control in adults following surgical intervention as a paediatric brain tumour patient. Whilst these findings do not specifically relate to AOC, similarities can be drawn and generalisations made.

The findings of Honegger et al (1998) may help to explain the present findings as they found pre-operatively emotional distress was present in 50% of participants with AOC, and following surgery, there was a reduction in post-operative abnormal emotional reactions. Importantly, the present research was conducted with participants post-operatively, this finding of no significant difference in the present research may be due to a similar reduction in post-operative abnormal emotional reactions as previously highlighted. Alternatively, a further possible explanation of no significant difference could be due to the significantly difference result seen on the Toronto Alexithymia Scale. Where this measure is concerned with the ability to identify own feelings, describe own feelings and ability to think with external orientation, it could explain why this present finding was not significant. If participants with AOC struggle with the associated areas highlighted by the Toronto Alexithymia Scale, then the self-report measure used to understand emotions and individuals' regulation of their own feelings may not be best placed to understand this. Participants with AOC may find it challenging to answer questions about the regulation of feelings and emotions that they struggle to identify. Therefore, it may be better for future research to include family or carers to support the understanding of the emotion regulation of participants with AOC.

Furthermore, the findings can be understood as participants with AOC have undoubtedly experienced highly emotive moments, such as when receiving their diagnosis, going through invasive treatment and adjusting to life with a chronic illness. The experiences of these moments may have led to the development of healthy ways to cope with their emotions, resulting in participants with AOC regulating their emotions well. Alternatively, these experiences may have led participants with AOC to suppress or avoid their emotions, emotional-avoidance strategies have been noted in physical health research (Van Middendorp et al., 2008). If a participant with AOC was used to this way of functioning, then this may provide a sense of emotion regulation, however, this maladaptive coping strategy can have negative psychological effects.

Also, as discussed in 4.4.2.1, participants with AOC may have experienced secure attachment in childhood, this may serve as another protective factor, this time against emotional dysregulation. Research has found that in adulthood individuals may be better at regulating their emotions if they have secure attachment from childhood (Bedrov & Bulaj, 2018). The above points could explain the present research finding of no significant difference in emotion regulation. Lastly, participants with AOC may have felt embarrassed about their emotional experiences, whether in relation to their diagnosis or other life factors, and therefore in answering this questionnaire about emotion regulation, they may have not wanted to share the nature of their emotional difficulties, leading to no significant difference found. Existing literature that empirically tests emotion regulation demonstrates the presence of difficulty regulating emotions (Hu et al., 2014); however, it is likely in the literature where questionnaires are used, this may mask the difficulties experienced in regulating emotions. Therefore, given emotion regulation is a multifaceted mental process that influences mental health outcomes, there needs to be further practical tests of emotion regulation in the future.

4.4.2.4 Connor-Davidson Resilience Scale. The present research findings indicated that participants with AOC did not score significantly differently on their level of resilience compared with controls. This suggests that participants with AOC and controls have similar levels of resilience. The previous research of Daughter et al (2023) found that resilience is protective against psychological symptoms. The participants with AOC who reported experiencing psychological symptoms and demonstrated mental resilience had less negative impact from these symptoms. Given this previous finding, it could be expected that participants with higher scores of resilience would report lower symptoms of depression and anxiety, the researchers will explore this when writing up the present research for publication. The findings differ from the results of a recent systematic review that was conducted by Gheshlagh et al (2016) to understand the resilience of patients with chronic physical diseases. This review concluded that patients scored lower on resilience than healthy individuals.

Prior to collecting data, it was hypothesised that participants with AOC would have lower scores of resilience, however, upon reflection after conducting the research, it seems more likely that participants with AOC would have increased levels of resilience. Resilience can be defined as the ability to adapt or maintain stable mental health, despite adverse experiences (Wald et al., 2006). The diagnosis of AOC could be viewed as adversity and the ability to positively adapt to living life with AOC could signify a resilient person. Prior to a diagnosis of AOC, it may be that individuals have built resilience from a variety of sources including personal, biological and environmental-systemic (Herrman et al., 2011). It is possible that patients with AOC had normal or high levels of resilience prior to diagnosis, one impacting factor of this may have been having early caregivers that were supportive and sensitive to the needs of the child, fostering an increased level of resilience (Gunnar & Fisher, 2006). Furthermore, those with a personality trait of openness and a cognitive appraisal style that allows adversity to be cohesively integrated into one's self-narrative, also appear to have increased resilience (Herrman et al., 2011). Considering the characteristics of the individual prior to their diagnosis is important to understand how they may respond to adversity, including a diagnosis of AOC.

Moreover, considering the resilience of participants with AOC through the Ecological Systems Theory (Bronfenbrenner, 2000) can help to build an understanding of the development of humans whilst taking into consideration the interaction between the environment and the individual. Firstly, if throughout their life an individual diagnosed with

AOC has found themselves in an environment where they are well socially supported, such as by family, peers, and teachers, then they may have greater resilience (Herrman et al., 2011). Secondly, community factors can also contribute to resilience. Attendance at a good school, the opportunity to engage with sports and arts and limited exposure to violence, can all increase resilience. Therefore, it is possible that the environments that participants with AOC have found themselves in have positively contributed to their resilience, leading to the present research result.

4.4.2.5 Social Functioning Scale. The present thesis found that participants with AOC scored significantly lower on social functioning than controls. This suggests that a diagnosis of AOC is associated with lower levels of social functioning. The findings mirror what is seen in existing research as a common complaint after surgery includes social dysregulation (Castle-Kirszbaum et al., 2022) and when participants with AOC were compared with controls, they scored lower in social functioning with half of the participants with AOC unable to return to employment in the same capacity as they were able prior to surgery (Lucia et al., 2021). Further pre-existing literature that supports the present finding is where it has been recognised that the social networks of participants with AOC shrunk after diagnosis and socialising felt more challenging (Daughters et al., 2023). Also, brain fog has led to low self-esteem in social interaction, which in turn may reduce engagement in social interactions (Daughters et al., 2023).

Moreover, as discussed in Chapter One (pp. 20-22), the deficiency of the hormone oxytocin in patients with AOC can be understood to play a role and therefore have an impact on social bonds and behaviours (Carter, 2014; Carter et al., 2009). The theoretical underpinnings of the present research may serve to explain the significant difference in the social functioning of participants with AOC in comparison to controls. Also, at the final follow-up of participants with AOC, significant differences were noted in social functioning when compared with a healthy sample (Mende et al., 2020), and recommendations were made that prompt psychosocial intervention is needed to ensure patients with AOC can lead a high-quality life. The findings of the present study were found to differ from the result of Apra et al (2019), where most participants did not experience limitations after surgery and were able to recover functioning of social activities and daily life.

The present result may be understood in terms of hypothalamic involvement. Previous research has found that a risk factor for psychosocial stress could be hypothalamic involvement of the tumour (Lucia et al., 2024; Zhao et al., 2021). Therefore, those participants with AOC that have higher deficits in social functioning may have increased hypothalamic involvement and future research should look at this potential link. Furthermore, taking into consideration the significant results found in the present research, such as with symptoms of depression, anxiety, and fatigue, these may influence participants with AOC's ability to engage in a variety of social activities. For example, if a participant with AOC notices that they struggle with socialising following surgery, this may lead to avoidance of future social interactions. This can be understood using the Cognitive Behavioural Therapy framework and psychological support for this difficulty could prove to be beneficial.

Following diagnosis and treatment of AOC, the patient may experience a role change (Eagly & Wood, 2012). The roles that patients with AOC were successful with prior to diagnosis and surgery may include being a partner, a parent or an employee. Following surgery, the patient with AOC may struggle in their role as an employee, such as attending work full time or working from the office for all allocated working hours. This may lead to a reduction in social roles for reasons such as lack of time to attend medical appointments or coping with the symptoms of their chronic illness. Lastly, it is recognised that The Social Functioning Scale encompasses a wide range of areas of social functioning, in future research, it would be helpful to refine the assessment of each area of social functioning to help pinpoint the specific areas to target for intervention.

4.4.3 Physical Health Measures

4.4.3.1 REACT Scale. The results indicated participants with AOC had significantly more restrictions in life due to feelings about their weight, body shape or size than controls. Previous research has highlighted that participants with AOC experience significant weight gain following intervention (Daughters et al., 2023; Dogra et al., 2022; Duan et al., 2021) and at final follow-up, participants with AOC's weight was significantly higher than before surgery. Furthermore, previous literature has shown that pre-operative weight can impact post-operative weight (Apra et al., 2019; Koutourousiou et al., 2013; Wu et al., 2021) and both participants with AOC and clinicians working with patients with AOC reported weight gain as a primary concern (Daughter et al., 2023) and noted the impact weight gain can have on self-esteem, mood symptoms and social relationships.

Research has found that overweight individuals can experience weight stigma daily (Vartanian et al., 2014) and these experiences are damaging to the psychological well-being of those individuals and can lead to harmful behavioural consequences (Hunger et al., 2015). The daily stigma experienced may contributed to the negative self-appraisal and reduced self-esteem. Previous research has found that if it is more common within a social group to be overweight, then this may have less impact on the personal happiness of the individual (Pinhey et al., 1997). Participants with AOC may be a part of a social group where being overweight is not common, and this could lead to an increased sense of stigma and a reduction in personal happiness.

Explanations around weight gain have been offered, including potential hypothalamic dysfunction as a result of the tumour location (Apra et al., 2019). Therefore, if factors that impact the likelihood of weight gain are a result of biological changes, then this could lead to a sense of a loss of control and helplessness. Moreover, it was identified by Mende et al (2020) that all measured symptoms of AOC significantly reduced at follow-up, excluding weight gain. This might suggest that this is an ongoing and longstanding difficulty for patients with AOC, and could lead to avoidance of social situations due to feared stigma, which in turn could lead to the isolation of patients with AOC.

Due to the findings from our study, we support the recommendations made by Dogra et al (2022) as they identified a need for participants with AOC to be offered nutritionist support and counselling inclusive of lifestyle and dietary intervention to support significant weight gain. Where previous research has identified participants gaining significant weight, and the present research has identified how participants with AOC feel about how their weight impacts their lives, it is vital that intervention is offered specifically to manage weight gain. Also, it has been found that being overweight is significantly more common in AOC than in COC (Wijnen et al., 2017) and therefore future research should explore the impacts of this common weight gain in AOC. The present research offers a new perspective and novel insight into the understanding of the psychological impact of weight gain for participants with AOC and associated feelings about weight, body shape or size.

4.4.3.2 Chalder Fatigue Scale. The present study found that participants with AOC had significantly higher levels of fatigue when compared with controls. This suggests that a diagnosis of AOC is associated with higher levels of fatigue. The recent qualitative research conducted by Daughters et al (2023) found that fatigue was one of the most common physical symptoms that participants with AOC reported, the impact of fatigue was widespread with participants acknowledging it affected their social lives, self-esteem and mood. Furthermore, research has found that participants with AOC had significant differences in levels of fatigue both pre- and post-operatively when compared with a healthy sample (Mende et al., 2020), however, no significant differences were found in experiences of fatigue when AOC and primary brain tumour participants were compared.

Moreover, fatigue can impact the ability to engage in daily activities and function, it is understood to be debilitating and overwhelming for the individual (Cella et al., 2007). As a diagnosis of AOC is already debilitating and overwhelming for the individual, experiencing fatigue alongside this is likely to impact the psychological well-being of the patient and research has found that fatigue may be an early symptom of depression (Fava et al., 1990). It could be that the impact fatigue has on patients with AOC contributes to the cycle of low mood explained in 4.4.1.1.

Alternatively, the fatigue experienced by participants with AOC may serve as a signal to the body to rest (Matura et al., 2018). Where patients with AOC receive a diagnosis, it may be difficult to truly rest, due to the commencement of treatment, follow-up appointments and managing medication, alongside other activities of daily living. If a patient with AOC tries too soon after intervention to attempt to function to a similar level to prior to their diagnosis and surgery, this may be when the body signals it needs rest, as such with fatigue. It has been found that fatigue is experienced as a complication of radiotherapy in participants with AOC (Rutenberg et al., 2020). Therefore, various factors may be influencing the experience of fatigue in participants with AOC.

4.4.3.3 Impact of Vision Impairment Scale. The results of this measure indicated participants with AOC have significantly higher levels of visual impairment than controls. The previous research has widely acknowledged visual impairment in participants with AOC (Dogra et al., 2019; Mende et al., 2020; Muller, 2014) and this has been identified as the most common symptom to be reported at initial presentation (Lucia et al., 2021). The findings of the present research indicate participants with AOC continue to experience visual impairment post-operatively, this aligns with previous research whereby it has been identified that visual impairment is one of the most frequently observed long-term conditions in participants with AOC (Wijnen et al., 2017). Further research could expand on the ideas seen in the present research with the use of empirical testing of vision, it is likely that the visual impairment experienced by AOC has wider implications for the participants than presently recognised and further research could explore this.

Moreover, the psychological impact of visual impairment has been acknowledged, and research has identified that vision loss can have impacts on mental health, particularly on depressive and anxious symptoms (Boagy et al., 2022). This research acknowledges vision loss is almost always going to lead to a psychological impact and a move towards acceptance could be helpful. Therefore, the Acceptance and Commitment Therapeutic approach could be helpful when working with participants with AOC who have significant visual impairment. Furthermore, visual impairment may impact the ability of patients with AOC to continue with employment, socialise and engage in hobbies. If visual impairments impact these areas of life, this can lead to lower levels of mental health, social functioning and quality of life (Nyman et al., 2009).

Previous research showed that visual deterioration can occur after surgery or radiotherapy (Mende et al., 2020; Rutenberg et al., 2022), which supports our findings where participants with AOC report significantly higher levels of visual impairment than controls. However, conclusions from other research differ, such as when it has been concluded that there is an improvement in visual deficit, visual acuity and visual field impairment post-operatively (Apra et al., 2019; Frio et al., 2019).

4.4.4 Satisfaction with Life Scale. The results indicated participants with AOC scored significantly lower on satisfaction with their lives than controls. This suggests that a diagnosis of AOC is associated with lower satisfaction with life. The findings mirror what is seen in existing research, where the quality of life in participants with AOC has been compared to a healthy patient cohort, significant differences were found in mostly all areas of life (Mende et al., 2020) and when participants with AOC have been compared with pituitary macroadenoma participants, the participants with AOC have scored lower on quality of life (Patel et al., 2015). Whilst not a significant finding, when participants with AOC have been compared with a healthy population, they have scored lower in their quality of life at long-term follow-up (Lucia et al., 2021).

The previous research has acknowledged that participants with AOC suffered a worse quality of life than those with COC (Kendall-Taylor et al., 2005) and when participants with AOC were compared with the general population, they had a worse quality of life at almost a decade after treatment (Gautier et al., 2012). The present research found significant differences between participants with AOC and controls in various areas, it might be expected that due to these significant differences, the overall satisfaction with life would be impacted. Therefore, two multiple linear regressions were conducted to understand how satisfaction with life can be explained in participants with AOC.

Furthermore, research has identified that negative life events can be significant risk factors for psychological distress and reduced satisfaction with life (Marum et al., 2014). It was concluded that negative life events were connected with increased psychological distress and reduced satisfaction with life. The present findings can be understood considering the diagnosis and implications of AOC being a negative life event, and therefore leading to increased psychological distress, such as with depressive and anxious symptoms, leading to significantly reduced satisfaction with life. Moreover, understanding the impact of the various psychological and physical symptoms that a participant with AOC may experience can aid in understanding why satisfaction with life may be significantly reduced. Then if it is further considered that these participants may not be able to access the appropriate psychological support that they require, it can be understood why quality of life may be reduced over a long period of time. This issue and future implications for clinical practice and policy are discussed later in this chapter.

4.4.5 Multiple Linear Regressions

While the present research recognised the importance of identifying the differences between participants with AOC and controls, to pinpoint specific targets and develop interventions for patients with AOC that will ultimately enhance their quality of life, it is also crucial to comprehend the current factors contributing to the poorer quality of life experienced by participants with AOC. Consequently, multiple linear regressions were conducted to ascertain whether psychological or physical variables can explicate the variability in life satisfaction, as well as the proportion explained by these variables.

Multiple linear regressions were carried out to understand to what degree satisfaction with life in participants with AOC can be explained separately, by psychological and physical health factors. Psychological variables explained 58.6% of the variance in satisfaction with life scores, while physical health variables explained 26.6% of the variance in satisfaction with life scores in participants with AOC. The regressions suggest that psychological variables explain more variance in quality-of-life ratings than the physical health variables. The findings of the present study support what has been seen in research previously: the findings of Vázquez et al (2015) indicated that individuals with psychological difficulties had a noticeable decrease in their satisfaction with life. Importantly, this negative impact on quality of life was significantly greater than the decrease in quality of life when considering physical health concerns. This finding mirrors the present study, emphasising the importance of targeting psychological well-being when working towards improving patients' satisfaction with life.

Of the psychological predictors, self-esteem and anxiety scores significantly predicted greater life satisfaction. Given the literature explored throughout the present thesis, it can be understood why improved self-esteem would positively impact quality of life. A participant with AOC and good self-esteem may feel more able to engage in enjoyable hobbies and feel a greater sense of achievement in doing so. Surprisingly, higher levels of anxiety significantly predicted an increased satisfaction with life, this is an unexpected finding. One potential explanation could be that strong motivation and low level of anxiety have been seen as significant factors precipitating success in an educational setting (Ahmetovic et al., 2020), but moderate to high levels of anxiety are often debilitating and would result in reduced satisfaction with life due to the symptoms associated with this. Furthermore, higher depression scores trended towards significantly predicting lower life satisfaction, this aligns with previous literature. On the other hand, the remaining measures were not significant predictors of the quality of life for participants with AOC (alexithymia; resilience; emotion regulation; social functioning). Firstly, where initial analyses found participants with AOC have significant differences in alexithymia scores and social functioning when compared with controls, it might be considered that although participants with AOC have difficulty with identifying their feelings, this will not necessarily lead to reducing their satisfaction with life. However, existing literature suggests that reduced social functioning will negatively impact the quality of life (Mende et al., 2020; Zada et al., 2013), and therefore there is a lack of understanding of why this result was not significant. Secondly, in the initial analyses, no significant differences were found in the resilience and emotion regulation of participants with AOC when compared with controls. Therefore, in the regression, the similar level of resilience and emotion regulation may suggest that these are not areas of great difficulty for patients with AOC and therefore they do not significantly impact on quality of life.

Of the physical health predictors, fatigue was a significant predictor of lower life satisfaction. The understanding of fatigue built throughout the present thesis builds an expected result, if a patient with AOC is highly fatigued, this may negatively impact various areas of life, leading to less meaningful engagement and reduced satisfaction. Conversely, weight stigma and vision impairment were not significant predictors, this may be due to the resilience of participants with AOC and them being able to cope well with these challenges. Furthermore, there may be other physical health predictors that have not been explored within the present research that have more of an impact on participants with AOC.

In Chapter One of the present thesis, attention was drawn to the abundance of literature concerning the physical health difficulties and complications commonly seen in participants with AOC and the dearth of literature regarding the psychological health of participants. Much attention is focused on physical health, with psychological health often being neglected or an afterthought. However, the results of the regressions suggest that the focus of research and care should be equally focused on physical and psychological aspects. The focus on psychological health alongside physical health, could allow for significant improvements and increased quality of life for patients living with AOC. Previous literature (Mende et al., 2020) has highlighted that when participants with AOC were compared with controls, the difference in physical functioning was less distinct than the difference in psychological functioning (role; emotional; cognitive; social). This provides further sustenance in the statement that psychological health should be treated as critical to address.

Furthermore, the results of the regression shed light on the importance of practice, policy and future research focusing on prioritising the psychological health of patients with AOC. Moving forward, the effective management and treatment of AOC should include the assessment and treatment of psychological health. Taking a more holistic approach to the care of patients with AOC, considering all comorbidities with equal importance, will allow the opportunity for optimum outcomes for patients.

4.4.6 Summary of Study One

The findings of Study One have highlighted that AOC causes widespread psychological difficulties for participants, and these psychological difficulties explain a high percentage of their satisfaction with life. With the use of existing psychological models and theories, the experiences of participants with AOC can be understood through a variety of lenses. This understanding of the difficulties that a participant with AOC might experience can help to comprehend the significant and complicated impact a diagnosis of, and living with AOC can have. The findings highlight the need to consider the whole person, considering both their physical and psychological experiences, to holistically work with the patient with AOC to ultimately improve their overall wellbeing

4.5 Interpretation of Study Two Results

The results of Study Two indicated no significant differences between participants with AOC and controls in the categories selected to analyse social and emotional appraisal of short video clips. The results of Study Two can be interpreted with consideration of reduced sample size, potentially compromising the study's statistical power. The theoretical underpinning of the present thesis is important with regard to Study Two as disruption of the pituitary gland resulting in an oxytocin deficit can be understood to impact social and emotional functioning (Daubenbüchel et al., 2016; Daughters et al., 2017; Hubble et al., 2017). Given that participants with AOC experience this disruption of their pituitary gland and the associated hormone deficiencies, despite the present results, this does not rule out the differences patients with AOC may have in their social and emotional experiences from the general population.

Firstly, the measure of emotion regulation in Study One did not find significant differences between participants with AOC and controls, further to this, there was no significant difference in the "emotion" category in Study Two. Whilst significant differences were expected, this may suggest that the measures used did not capture what was set out to be understood by participants with AOC. Secondly, in Study One, significant differences were found in social functioning when comparing participants with AOC to controls. This finding would have led to further expectations of significant differences in the “social” categories in Study Two, however, this was not found. The lack of significant differences found within Study Two could be due to the online nature of the study. When capturing social and emotional responses, it may be that doing so online, compared to in-person, has an impact on the individual’s attention and appraisal of the situation. If the social situations were observed in vivo then participants may have had a different response to this. Likewise, if participants were involved in the social situation and asked for feedback regarding their experience after, this may yield helpful data about the social and emotional experiences of participants.

The present findings differ from the research whereby it has been found participants with AOC score lower in social functioning and they experience social dysregulation (Castle-Kirszbaum et al., 2022; Lucia et al., 2021). It is possible that neither the participants with AOC or controls picked up on the social aspects of the videos and they provided less detailed responses than the researchers were hoping for. As mentioned earlier in this chapter, the significant differences in alexithymia between participants with AOC and controls may explain the difficulty participants with AOC had in interpreting others’ emotions throughout the videos. Whilst alexithymia refers to difficulties identifying one’s own emotions, this is closely linked to identifying the emotions of others (Bird & Viding, 2014).

In conclusion, this study was the first attempt at an empirical design investigating participants with AOC, and despite the lack of significant results, it is worth following up on this idea with further empirical testing of social and emotional functioning. Ideas for future research ideas are discussed in section 4.8.3.

4.6 Experiences with Participants with AOC

The present research highlighted the investment that participants with AOC have in ongoing research, and this was shown in communications with the researcher via email. Firstly, some participants with AOC expressed interest in taking part in further research, stating they (a) “would be happy to take part in a conversation” (b) “please do keep me in mind for any other [studies] ones” (c) “if you need any more information…I’d be more than happy to take part”. Another participant offered to support the researcher in reaching a wider audience of patients with AOC asking, “Would you like to collaborate”. Furthermore, several participants were curious why the researchers were focusing on AOC “I’m just interested as to why you chose this as a study” and “I am curious…why you are researching this particular area”, highlighting their surprise at research focusing on this area, suggesting a lack of existing literature. This came with an expression of gratitude from some participants (a) “I am grateful for the time and interest you and your supervisor are taking” (b) “It's really reassuring to know there are people out there looking for answers”.

Likewise, participants acknowledged the research into AOC may likely help them “chances are it could benefit me” and that the research was “valuable work”. The opportunity to contribute to research was valued by a participant as “it helped [them] frame some experiences [they’ve] found challenging” and another participant was “really interested to read about…findings”. Finally, a few participants highlighted the lack of peer support and ability to share experiences of AOC with others, stating “I don’t know anyone else with AOC” and “I’ve never actually met anyone else who has had the same diagnosis”. These communications show that the participants with AOC, themselves, recognise a need for their psychological needs to be better understood, and they see real value in further research to gain greater understanding. These communications with participants with AOC highlight the continued interest in research and the need to continue this important work, in turn supporting the findings and recommendations from Daughters et al (2023).

4.7 Strengths and Limitations of the Present Studies

4.7.1 Design

The online nature of the present thesis may have excluded certain potential participants. It may be that patients with AOC with extreme visual impairment or those with severe fatigue, who could be most at risk of psychological impacts, were unable to participate in the research. Likewise, those patients with AOC who experience the greatest psychological impact, such as extremely low mood or extremely heightened anxiety, may find it difficult to participate in research and have their experiences captured. Researchers could have offered postal questionnaires for Study One and face-to-face participation for both studies. However, the researchers tried their best to support all patients with AOC to participate. A strength of the online nature of the present studies is that this allowed data collection to take place from various locations and may have increased the overall number of participants able to participate. Likely, many participants with AOC would not have been able to travel to the researcher's base, therefore the online nature of the research allowed the opportunity for a wide range of participants to take part without the need to travel.

There was a high attrition of participants with AOC from Study One to Study Two. One reason for this attrition could be explained by the technical difficulties reported by participants with AOC when attempting to complete the second study. A limitation is that the researchers were unable to troubleshoot some participants who reported difficulties despite best efforts, therefore leading to the dropout of participants with AOC who were keen to contribute to the research. However, the researchers were able to troubleshoot for several participants with AOC which led to them taking part in the study. Moreover, all data was collected after participants with AOC had undergone treatment, it would be interesting for future research to collect data on patients with AOC at different points in their treatment journey and recovery. Despite this, it is a strength that the present research was able to capture the long-term psychological impact of AOC.

The quantitative nature of the present thesis was a strength as the researchers were able to analyse data and identify patterns whilst testing the hypotheses. The conclusions drawn from the quantitative studies have led to important implications being made. The present thesis had a strong study design as there were matched control groups for each study. Having matched controls in the present studies reduced the chance of confounding variables, such as age and country of residence, explaining any significant difference found between the groups and therefore enhancing the validity of the studies. Furthermore, a pre-registration was completed for both studies, this improves the credibility of the findings. Lastly, data sharing and open science practices are being followed within this research which aims to make the research more accessible and transparent.

4.7.2 Sample

Whilst the researcher collected information regarding the geographical location of participants, the ethnicity of participants was not recorded. Although the researcher is not aware of any differences in quality of life in AOC controlling for ethnicity, this cannot be ruled out and should be included in future research. Relatedly, as the researchers originally planned to recruit participants from one country, signposting for accessing mental health support was limited to the UK. In future research, global options for mental health support should be included to ensure all participants get the most appropriate support.

Initially, the study cohort was a selective cohort listed on a database with those who previously agreed to be contacted about future research opportunities, which may have limited generalisability and validity of findings. However, the selective cohort database did not generate the expected number of participants and therefore further sampling methods were drawn on. Participants with AOC were recruited via charities and social media. Whilst this delayed recruitment, a strength of this is that the present sample may be more generalisable to other patients with AOC, therefore increasing validity. The sample was representative of the population with AOC, with participants covering a wide geographical location (six different countries). This increases external validity to the wider population with AOC and limits bias towards one country.

The researchers struggled with recruitment and worked exhaustively to recruit a satisfactory number of participants with AOC, and therefore a strength of the present research is the sample size. The expected participant number was lower than stated in the pre-registration which may reduce power, however, compared to other studies of this population, we achieved a satisfactory number of participants. If previous quantitative research on AOC is considered, the present sample size is hoped to be a representative and appropriate number to understand patients with AOC. For example, of the prospective studies included in the literature review in Chapter One, the average number of participants with AOC was 19 in the prospective studies (Daughters et al., 2023; Lucia et al., 2021; Mende et al., 2020; Patel et al., 2015). Furthermore, the average number of participants with AOC across all studies included in the literature review, both retrospective and prospective, was 53. Whilst this number is somewhat higher than the present studies' sample sizes, the retrospective research included had sample sizes much above the average. There may be many factors contributing to the difficulties with recruitment, and a key factor may be the rare nature of AOC, therefore, the number of participants with AOC who were able to take part is a strength.

Additionally, because participants with AOC were recruited from six countries, it is important to consider the different health systems that participants with AOC have access to in each country. In some countries participants with AOC resided in, healthcare was free to access, and in other countries, healthcare is paid for privately. Considering the social class and economic status of participants with AOC would be important in future research as this would support understanding of ease of access to support and outcomes. Another influence on outcomes is timely access to diagnosis and treatment, in some countries, it may be difficult to access professional support and therefore diagnosis and treatment may be delayed, whereas in a country where healthcare is easily accessible, diagnosis and treatment may occur in a timely manner. Although the overall sample size for each study was good, it was not possible to break analyses down based on country of residence as this would have resulted in much smaller groups and any interpretation of findings would be extremely difficult, and as such these analyses were not investigated. However, it is acknowledged that this may be an important factor to consider when discussing quality of life and the psychological impact of AOC and should be included in future research.

Furthermore, selection bias may have been present in our sample and it is not possible to say which bias may be favoured. There are two possible ways in which bias may have been present, firstly, patients with AOC who experience greater psychological difficulties may have been more willing to participate in the study, or, secondly, patients who do not experience great psychological difficulty may feel more able to engage in research and share their experience. It is not possible to conclude if the sample is biased in either way, however, with the approach to recruitment of participants, it is thought that the sample is representative of the population.

Whilst the researchers did gather information regarding whether participants with AOC had undergone surgery as part of treatment, the details of the type of surgery were not gathered. Further details such as tumour location, tumour type, and the size of the tumour were not gathered. Although it was not feasible for the present thesis, this information should be included in future research. There is evidence that the extent of hypothalamic involvement of the tumour relates directly to the extent of psychological impact (Daughters et al., 2023;

Lucia et al., 2024; Zhao et al., 2021), therefore, further exploration of the influence of the extent of hypothalamic involvement and psychological wellbeing is vital.

Finally, participants with AOC had to provide documentation to confirm their diagnosis of AOC. This may have limited the number of participants taking part, firstly due to patients with AOC potentially not having confirmation of diagnosis easily accessible and secondly, there may have been ambivalence in sharing these documents with researchers whom they did not have a pre-existing relationship with. However, on balance, the researchers felt it was critical to ensure that only patients who could evidence a diagnosis of AOC are included in the research and that ultimately it is a strength that all participants with AOC in the present studies are confirmed to have a diagnosis of AOC.

4.7.3 Measures

As is common with quantitative research that involves the use of numerous measures, there was potential for participant response fatigue. Therefore, the researchers considered this and to minimise this, the measures included were carefully chosen. Firstly, there were options of measures that captured similar psychological areas, the most appropriate measure was chosen considering it would be presented alongside various other measures. Secondly, to reduce the chance of response fatigue, in Study One, there was no time limit in which the measures had to be completed, and in Study Two participants could take a break halfway through the videos.

Whilst the measures were carefully chosen to best capture a holistic understanding of participants' psychological well-being and following insights from previous research (e.g., Daughters et al., 2023), there may be other areas of psychological functioning that are impacted by AOC that have not been explored within the present theses. Within the multiple linear regression, there was still an amount of variance that was not accounted for, further research, with the inclusion of alternative psychological measures, may be able to account for a higher variance in satisfaction with life. However, a strength of the research is that the psychological predictors in the multiple linear regression did account for a high percentage of variance in satisfaction with life for participants with AOC. This is a novel finding that the measures selected captured this.

With regards to Study Two, it is possible that the LIWC software's dictionary-based approach where there is reliance on the pre-defined list of words may have missed nuance in the responses of participants. However, it is a strength that Study Two used the LIWC software to attempt to capture the social and emotional responses of participants given that LIWC has previously helped researchers to understand language style and how this connects with social relationships and emotionality (Tausczik & Pennebaker, 2010).

Moreover, Study One used gold-standard psychological measures with good to excellent reliability. The present research findings were more robust due to increased validity and comparability across previous and future research. The measures utilised in the research comprehensively covered psychological and physical well-being, making it possible to gain a better understanding of the psychological well-being and functioning of participants with AOC than in previous research. In conclusion, considering all strengths and limitations, the present research makes a significant and novel contribution to the existing psychological knowledge base on AOC. The present studies are original and provide insight into an area of research often overlooked in patients with AOC.

4.8 Implications

4.8.1 Implications for Practice

The present studies highlight the psychological impact of AOC, supporting the recommendation for psychological well-being to be considered at all stages of a patient journey, ensuring holistic and patient-centred care. Suls & Rothman (2004) stated "Too often, the findings and implications of basic research do not make their way to clinical practice and intervention. This can be as much the fault of researchers as clinicians”. In the researchers’ dual role as a clinician and researcher, the below implications are stated with the hope that the findings of this research find their way to clinical practice and impact on intervention offered to patients with AOC.

Firstly, healthcare professionals working with patients diagnosed with AOC should have open conversations about mental health and psychological well-being, whether this be at diagnosis or throughout the process of treatment. The conversations should be routine and could lead to comprehensive care plans taking every need of the patient with AOC into consideration. If conversations about mental health and psychological well-being are being initiated by healthcare professionals, then the healthcare professionals also must know how to respond to any difficulties that are shared by patients, having appropriate signposting options for support dependent on the difficulties of the patient. Moreover, it might be necessary for healthcare professionals regularly working with patients with a diagnosis of AOC to attend training courses on mental health and psychological well-being. It would be necessary for those staff who are trained medically to understand mental health and psychological well-being, and those staff who specialise in mental health treatment, to build an understanding of AOC and the physical impact of this diagnosis.

Secondly, it is widely recognised that there is a disconnect between care for mental and physical health (Naylor et al., 2016). The publicly funded healthcare system in the UK is the National Health Service (NHS). Within the NHS, some services support the psychological needs of those diagnosed with cancer, including malignant brain tumours. There are psychological services embedded within cancer services (Guy’s and St Thomas’ NHS Foundation Trust, 2023; Mid and South Essex NHS Foundation Trust, 2024) and to access these services, patients must be accessing treatment for cancer within the hospital, however, these services are not accessible for patients with AOC due to the benign nature of their tumour. Whilst the researchers recognise the difference in diagnoses, it is necessary for the expansion of existing NHS services to include the support and treatment of the psychological needs of those with AOC. Indeed, this idea was supported by both participants with AOC and clinicians treating them (Daughters et al., 2023). When participants with AOC were compared with participants with primary and secondary brain tumours, no significant difference in quality of life was found (Mende et al., 2020). This finding supports the idea that patients with AOC should have equal access to psychological services. Additionally, an integrated approach toward physical and mental health would be beneficial and has been identified as a priority in NHS policy (NHS England, 2019). If psychological services were better integrated within hospitals and outpatient clinics, then this may improve the ability to offer mental health support alongside any physical health treatment. There has been a growing commitment to the integration of physical and mental health care in the NHS (Naylor et al., 2016; Psychological Professions Network, 2023) and it has been recognised that holistic care for patients helps to secure improvements in both areas of health.

We cannot conclude a mental health diagnosis from the results of this study, due to the use of clinical screening tools, but the results strongly indicate the important areas of mental health and psychological well-being and the most problematic symptoms that should be targeted by intervention. In the long term, however, it would be necessary to increase the offering of specialised services that offer support to patients with AOC. These services would be able to offer tailored therapeutic approaches that take into consideration the complex psychological impact of a diagnosis and living with AOC.

Conducting this research has highlighted the limited awareness of this diagnosis and its impact, across healthcare professionals. Within practice, awareness needs to be raised. This may be done by presenting at trust-wide psychological services conferences and disseminating research findings through appropriate avenues such as the staff bulletin and on the intranet page. Lastly, self-help materials could be developed specifically for individuals with AOC. These self-help materials could be focused on several modalities, namely Cognitive Behavioural Therapy or Compassion Focused Therapy. Farrand & Woodford (2015) found some evidence that supports cognitive behavioural self-help for depression, whilst Sommers-Spijkerman et al (2018) found compassion-focused self-help was a promising mental health approach for improving general well-being.

4.8.2 Implications for Theory and Policy

The present research has drawn attention to a need to increase funding for mental health resources and improve service accessibility for patients with AOC. Firstly, conversations need to be had at a policy level, such as in commissioning meetings where services are monitored, planned and purchased (Wenzel et al., 2023). Commissioners can be made aware of the lack of support available for patients with AOC and how they are excluded from various support avenues due to the non-cancerous nature of the tumour. The psychological needs of patients with AOC appear to have been dismissed or forgotten about. Commissioners need to consider a pathway for psychological care of patients with AOC and the first steps in this happening will involve raising awareness. Secondly, it would be helpful to audit NHS services, building knowledge of the number of patients with AOC receiving care from the individual NHS trusts. With the knowledge of the number of patients receiving care, commissioners would then be able to allocate the necessary funding to support those patients.

Moreover, the classification of craniopharyngioma has led to the exclusion of support for patients with AOC. For example, some charities that were approached to advertise the present research studies declined to advertise due to the classification. If this is considered in the context of those trying to access support, we might understand support as being limited. The National Institute for Health and Care Excellence (NICE) guidance provides evidence-based recommendations for the health and social care sector for the management of conditions and diseases. Unfortunately, NICE has not published specific guidelines for the treatment of craniopharyngioma in either child or adult populations. Additionally, to the best of the researcher's knowledge, no other evidence-based guidelines exist so there may be no clear consensus on the best psychological treatment for patients with AOC. Evidence-based guidelines must be developed as they can influence theory and policy and enable the best psychological support for the needs of all patients with AOC.

Furthermore, the research highlighted that there were significant differences between participants with AOC and controls. These findings suggest a need for funding to be made available to develop interventions to improve the areas of psychological functioning identified in the present study and previous literature. This would include interventions to address low mood, anxiety, social functioning and satisfaction with life. These areas that have been highlighted by the present research can help with working towards a psychological model of understanding the impact of AOC. The present research studies shed light on the areas of significant impact for participants with AOC which could be applied to a model. If future research can show the effectiveness of intervention for psychological difficulties in participants with AOC, then this could help lead to changes in policy to expand access to such interventions.

4.8.3 Implications for Future Research

The present thesis has drawn attention to the various areas of future research that would be advantageous to patients with AOC. Firstly, there is a need for longitudinal research, while the present research captured a glimpse of patients with AOC experiences at a particular point in time, future research should aim to explore long-term mental health and psychological well-being trajectories, to explore how psychological well-being evolves. For example, at diagnosis, pre-intervention, post-intervention and 2-year follow-up. The literature review carried out earlier in the present thesis shed light on the abundance of case studies, future research should be focused on broad and large-scale studies so that research findings can be generalised to the wider patient population with AOC. Furthermore, literature exists that explores the long-term physical health impact of AOC (Cohen et al., 2011; Crom et al., 2010; Muller, 2015), however, to the best of the researcher's knowledge, this literature does not currently exist for the long-term psychological impact. Thus, this would be a beneficial future research focus.

Additionally, further research should be conducted to develop a clearer understanding of the psychological impact in the areas identified where significant differences were identified in participants with AOC when compared with controls. For several reasons, shorter questionnaires were used as part of the present research, therefore in future research, more extensive questionnaires could be used to explore the areas of interest, or qualitative research could be conducted to gain a more detailed understanding. The present research used general measures, due to there not being a specific instrument for use with the population with AOC, it could be helpful for future research to focus on the development of an AOC-specific measure that can be used widely across clinical practice and research with this patient group.

Moreover, future research could investigate the application and use of different therapeutic modalities when working with patients with AOC. This research should measure outcomes before the intervention and after. This may build the evidence base and aid in understanding the therapeutic modality and type of intervention that should be offered to patients with AOC. Future research could look specifically at trauma in patients with AOC, it is possible, as a result of intervention and experiences of having AOC, there may be experiences of trauma. Research identifies trauma as a result of a variety of physical health conditions and treatments associated with them (Wiseman et al., 2013). This has not previously been explored in AOC, however, it may be an area of interest for future research.

The process of conducting the present research has drawn attention to the limited research looking at the experience of caregivers who support those with craniopharyngioma. Previous research involving caregivers has focused on COC (Beckhaus et al., 2024), therefore, future research would be beneficial in helping to understand how being the primary caregiver for a patient with AOC impacts an individual. Research extensively reports the impact being a caregiver, in any context, can have on psychological well-being highlighting the importance of further consideration of this topic. It has been indicated that those who provide unpaid care are at higher risk of experiencing anxiety and depression (Redican et al., 2024). Lastly, further involving caregivers to understand how they perceive the psychological well-being of the patient with AOC would be beneficial in building a comprehensive understanding.

Moreover, if future research were to be conducted with patients with AOC using LIWC software, it may be recommended that a different study design would be a better fit. Future research could use fewer videos that have a longer duration with the same typed response online, or the study could take place in person where the participant watches the video followed by a verbal discussion with the researcher about what they observed which is later transcribed and then this is put forward for analysis in LIWC. The findings of qualitative research conducted by Daughters et al (2023) and the anecdotal evidence from the researcher's experience of conducting the present thesis demonstrate that participants with AOC are in strong support of further research and investment into their psychological well-being. Therefore, this should be a priority of research moving forward.

4.9 Self-Reflexivity

Before completing the present thesis, I had limited awareness of craniopharyngioma. I had a greater knowledge of cancerous brain tumours but little awareness of non-cancerous brain tumours. However, upon learning about craniopharyngioma and discussing options of research related to it, I felt a strong sense of wanting to complete my research focused on patients with AOC due to the limited understanding of the psychological experiences of this group. It is also important to note that I have not had personal experience with craniopharyngioma, and this will have shaped my approach to the research. I felt empathy for the patients diagnosed with AOC and acknowledged the need for more individualised support for these patients.

Additionally, how I have framed the results and implications reflects my priorities and values. Recognising that I am a Trainee Clinical Psychologist, with a background of working in mental health, I have interpreted the results of the present thesis with my knowledge and expertise in mental health and psychological wellbeing. Predominantly, research into AOC takes place across a variety of disciplines including neuroscience and oncology, and it is less common for the research to be conducted within mental health and psychology. Throughout the research, I have built an in-depth understanding of the physical health aspects of AOC and I can apply these learnings to my work. This emphasises the need for holistic care for all patients, considering their physical and psychological needs. I feel hopeful that the present research studies will lead to further research considering the psychological impact of AOC.

Professionally, this research has highlighted the difficulty in accessing services for certain groups of patients. Patients may not meet referral criteria for standard services for psychological support despite having a clear need. There are complexities of accessing appropriate support for identified needs and the needs of patients with AOC can be neglected. This research has highlighted the importance in my clinical practice to consider those patients who may not meet service referral criteria, despite no other services being able to appropriately meet their needs. My awareness, due to family experiences, of difficulty accessing necessary support promptly, may have influenced my views on services meeting the needs of patients. Before and whilst conducting this research, I acknowledged the lack of timely mental health care available in the UK (Baker & Kirk-Wade, 2024; Gilburt & Mallorie, 2024) and this research has drawn further attention to this, specifically for participants with AOC.

Completing the thesis provided me with opportunities to develop transferable skills as a researcher and clinician. The process has involved problem-solving, such as with recruitment difficulties and I have had regular research supervision, which has supported key decision-making. Furthermore, I have developed my quantitative research method skills, which will be helpful when conducting future research and potentially supervising other research projects. These skills would be particularly helpful when working as a clinical psychologist and completing service evaluations. I hope that my learnings through this research positively impact on my practice as a clinical psychologist.

4.10 Summary and Conclusions

To conclude, the present thesis is the first to solely focus on the mental health and psychological well-being of participants with AOC. This research offers a novel insight into the psychological experience of participants with AOC and highlights the need for treatment and intervention to consider these experiences, alongside physical health, to support a holistic and person-centred approach.

The findings highlight those participants with AOC scored significantly worse on measures of depression, anxiety, understanding of own feelings, social functioning, weight stigma, fatigue and visual difficulties compared with controls. Ultimately, participants with AOC scored significantly lower on satisfaction with life compared with controls.

Conclusively, poorer psychological well-being and physical health both significantly predicted lower satisfaction with life in participants with AOC, with the psychological predictors explaining more than the physical predictors.

This original contribution to the literature highlights a need for comprehensive care of patients with AOC, prioritising both physical and psychological needs. This research advocates for the psychological needs of patients with AOC to be considered in clinical practice, theory and future research. Through this, a focus on the interface of physical and mental health can be prioritised to enable better outcomes for patients with AOC. Overall, the present thesis has offered an understanding of central areas of experience of patients with AOC, these should be prioritised moving forward with treatment for AOC.

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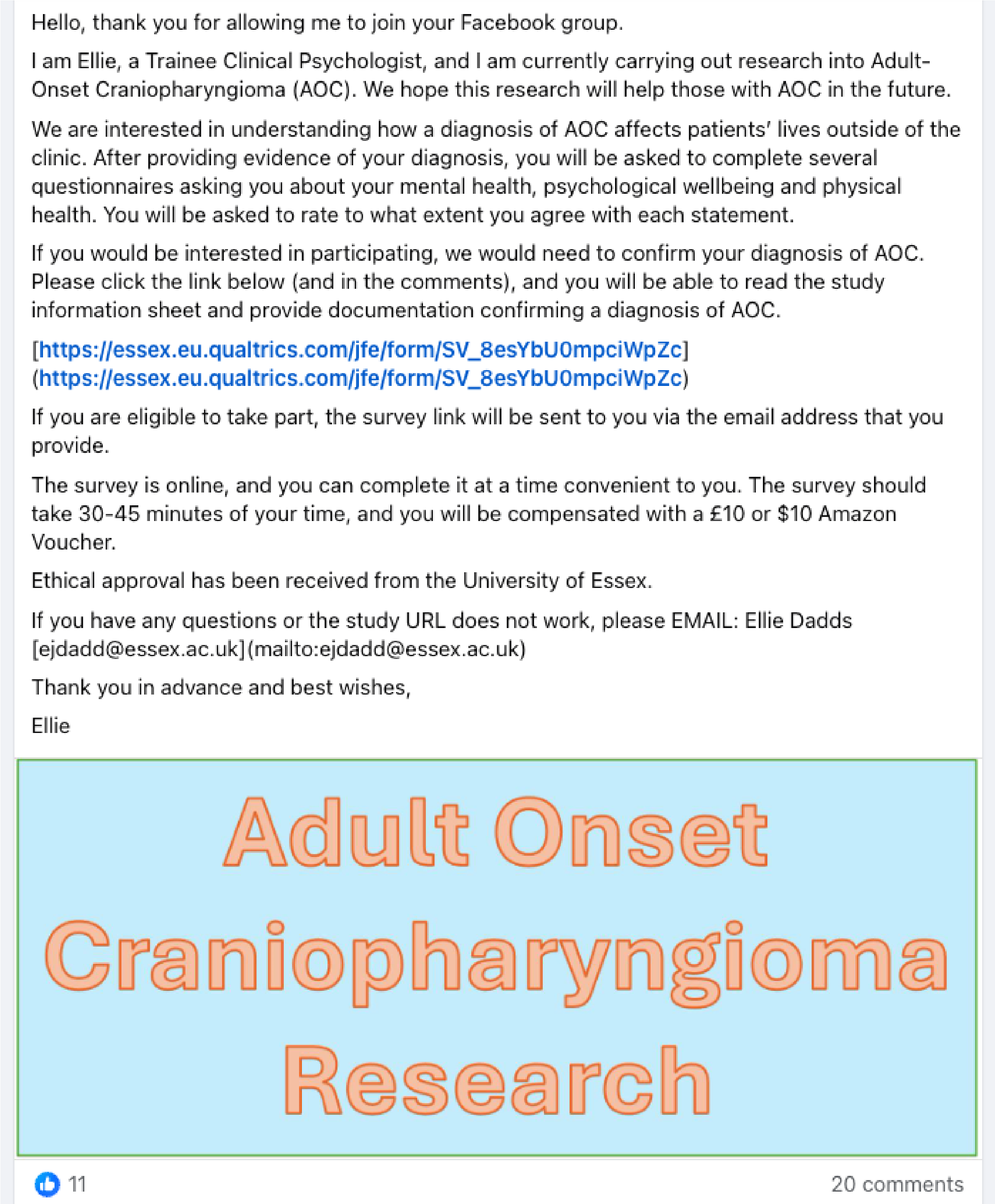
Appendix A

Study Advert on Facebook



Hello, thank you for allowing me to join your Facebook group.

I am Ellie, a Trainee Clinical Psychologist, and I am currently carrying out research into Adult-Onset Craniopharyngioma (AOC). We hope this research will help those with AOC in the future.

We are interested in understanding how a diagnosis of AOC affects patients' lives outside of the clinic. After providing evidence of your diagnosis, you will be asked to complete several questionnaires asking you about your mental health, psychological wellbeing and physical health. You will be asked to rate to what extent you agree with each statement.

If you would be interested in participating, we would need to confirm your diagnosis of AOC. Please click the link below (and in the comments), and you will be able to read the study information sheet and provide documentation confirming a diagnosis of AOC.

[https://essex.eu.qualtrics.com/jfe/form/SV_8esYbU0mpciWpZc]
(https://essex.eu.qualtrics.com/jfe/form/SV_8esYbU0mpciWpZc)

If you are eligible to take part, the survey link will be sent to you via the email address that you provide.

The survey is online, and you can complete it at a time convenient to you. The survey should take 30-45 minutes of your time, and you will be compensated with a £10 or $10 Amazon Voucher.

Ethical approval has been received from the University of Essex.

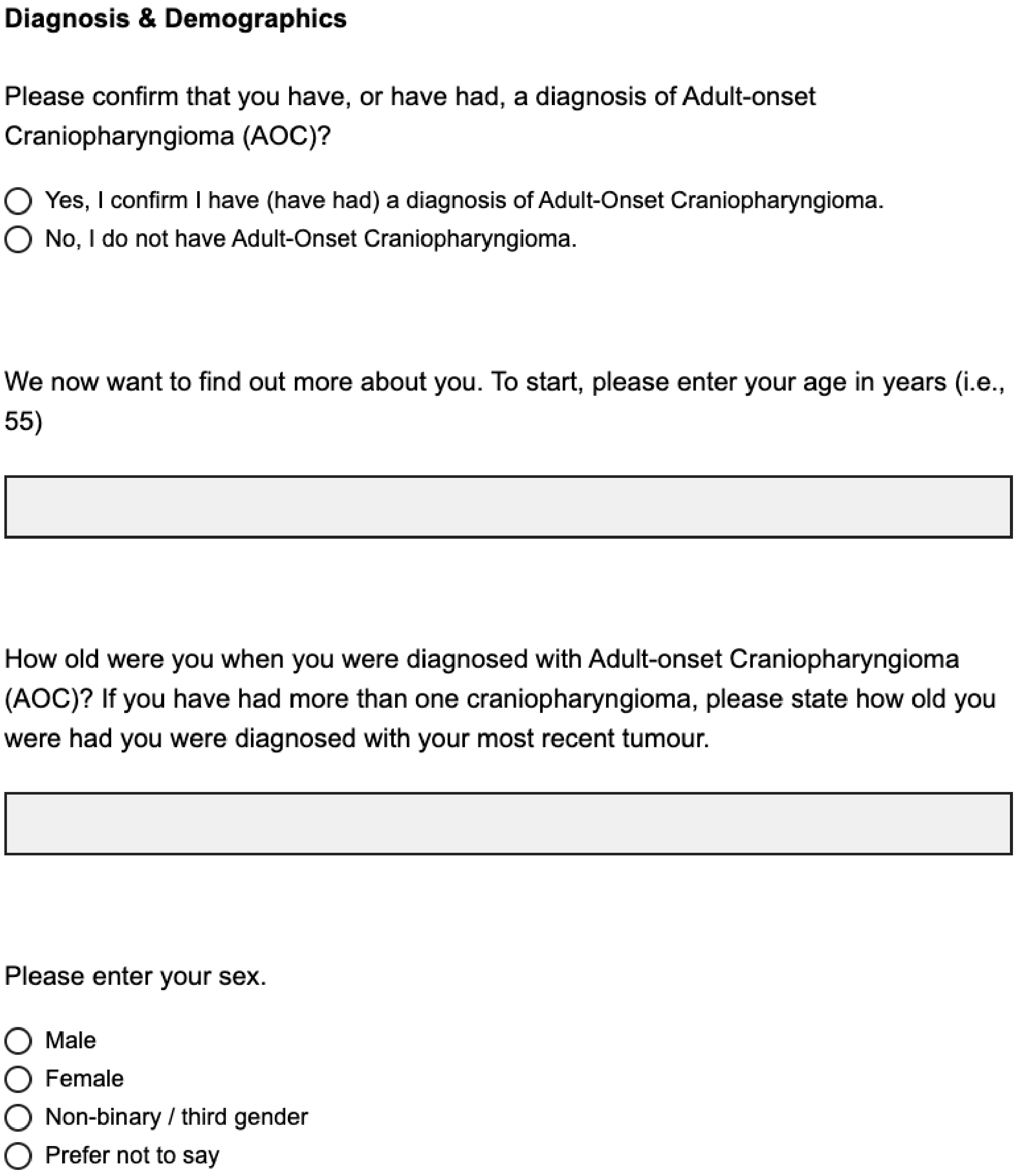
If you have any questions or the study URL does not work, please EMAIL: Ellie Dadds ejdadd@essex.ac.uk

Thank you in advance and best wishes,

Ellie

Appendix B

Study One Demographics



Diagnosis & Demographics

Please confirm that you have, or have had, a diagnosis of Adult-onset Craniopharyngioma (AOC)?

○ Yes, I confirm I have (have had) a diagnosis of Adult-Onset Craniopharyngioma.
○ No, I do not have Adult-Onset Craniopharyngioma.

We now want to find out more about you. To start, please enter your age in years (i.e., 55)

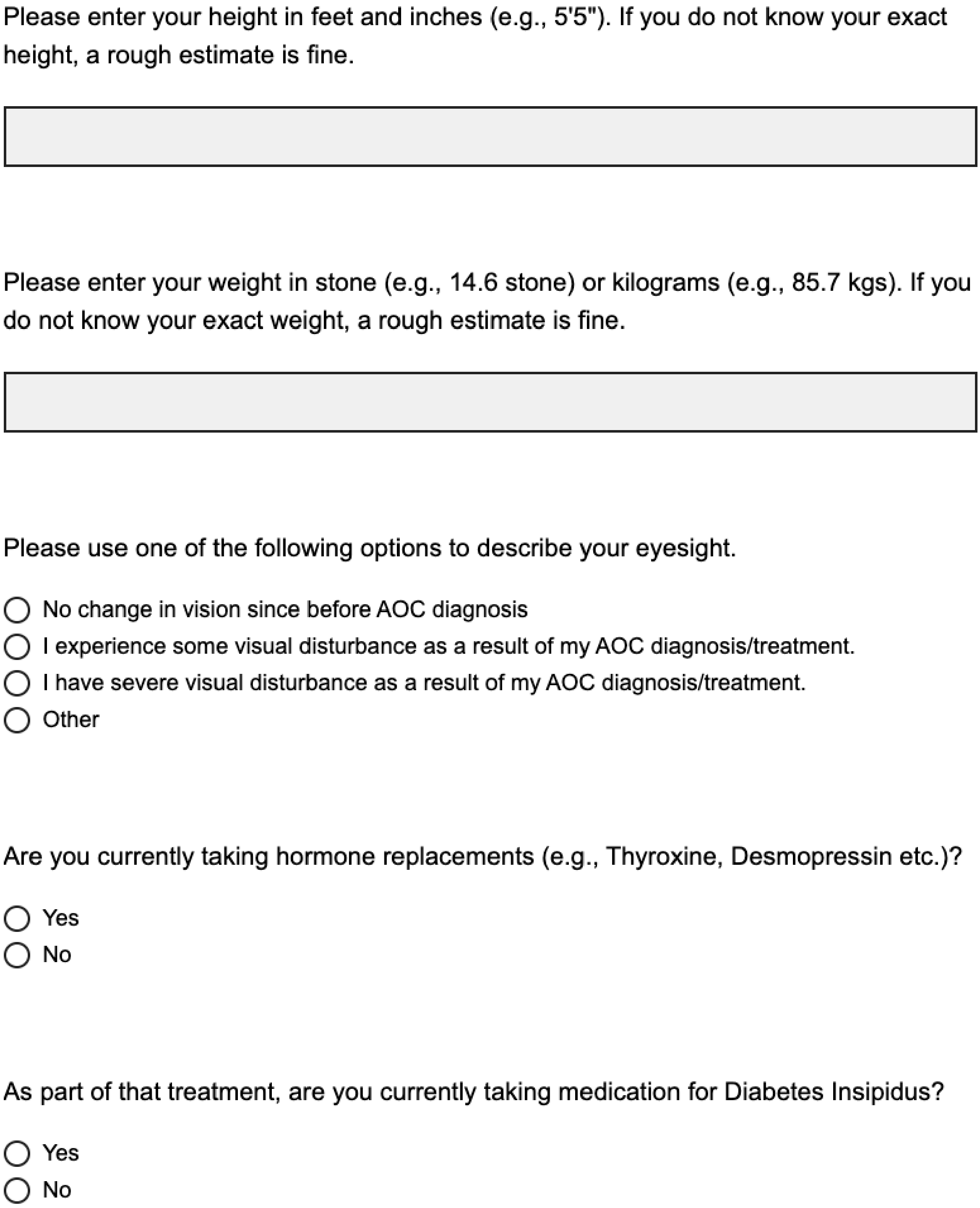
How old were you when you were diagnosed with Adult-onset Craniopharyngioma (AOC)? If you have had more than one craniopharyngioma, please state how old you were had you were diagnosed with your most recent tumour.

Please enter your sex.

○ Male
○ Female
○ Non-binary / third gender
○ Prefer not to say

Appendix C

Study One Medical History Questions for



Please enter your height in feet and inches (e.g., 5'5"). If you do not know your exact height, a rough estimate is fine.

Please enter your weight in stone (e.g., 14.6 stone) or kilograms (e.g., 85.7 kgs). If you do not know your exact weight, a rough estimate is fine.

Please use one of the following options to describe your eyesight.

○ No change in vision since before AOC diagnosis
○ I experience some visual disturbance as a result of my AOC diagnosis/treatment.
○ I have severe visual disturbance as a result of my AOC diagnosis/treatment.
○ Other

Are you currently taking hormone replacements (e.g., Thyroxine, Desmopressin etc.)?

○ Yes
○ No

As part of that treatment, are you currently taking medication for Diabetes Insipidus?

○ Yes
○ No

As part of that treatment, are you currently taking Growth Hormone?

○ Yes
○ No

As part of your treatment, have you undergone surgery?

○ Yes
○ No

As part of your treatment, have you undergone any radiotherapy?

○ Yes
○ No

Have you ever been diagnosed with a mental health disorder (e.g., anxiety, depression etc.)?

○ Yes
○ No

What mental health disorder did you/do you have?

Did you seek treatment for this disorder?

○ Yes
○ No

What treatment did you receive?

Have you ever self-diagnosed a mental health disorder (e.g., anxiety, depression etc.)?

○ Yes
○ No

What mental health disorder did you/do you have?

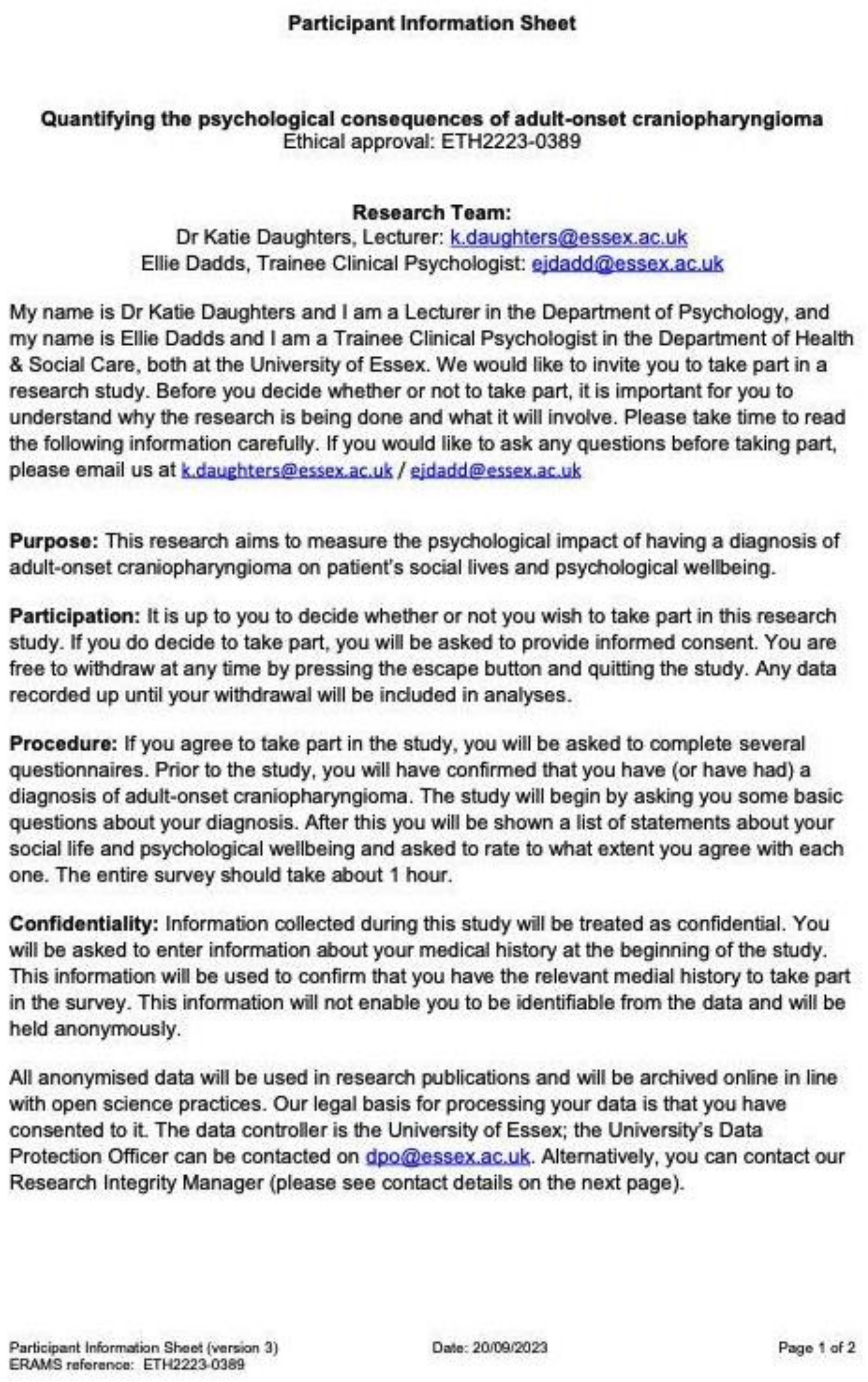
Did you seek treatment for this disorder?

○ Yes
○ No

What treatment did you receive?

Appendix D

Study One Participant Information Sheet for Patients with AOC



Participant Information Sheet

Quantifying the psychological consequences of adult-onset craniopharyngioma
Ethical approval: ETH2223-0389

Research Team:
Dr Katie Daughters, Lecturer: k.daughters@essex.ac.uk
Ellie Dadds, Trainee Clinical Psychologist: ejdadd@essex.ac.uk

My name is Dr Katie Daughters and I am a Lecturer in the Department of Psychology, and my name is Ellie Dadds and I am a Trainee Clinical Psychologist in the Department of Health & Social Care, both at the University of Essex. We would like to invite you to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. If you would like to ask any questions before taking part, please email us at k.daughters@essex.ac.uk / ejdadd@essex.ac.uk

Purpose: This research aims to measure the psychological impact of having a diagnosis of adult-onset craniopharyngioma on patient's social lives and psychological wellbeing.

Participation: It is up to you to decide whether or not you wish to take part in this research study. If you do decide to take part, you will be asked to provide informed consent. You are free to withdraw at any time by pressing the escape button and quitting the study. Any data recorded up until your withdrawal will be included in analyses.

Procedure: If you agree to take part in the study, you will be asked to complete several questionnaires. Prior to the study, you will have confirmed that you have (or have had) a diagnosis of adult-onset craniopharyngioma. The study will begin by asking you some basic questions about your diagnosis. After this you will be shown a list of statements about your social life and psychological wellbeing and asked to rate to what extent you agree with each one. The entire survey should take about 1 hour.

Confidentiality: Information collected during this study will be treated as confidential. You will be asked to enter information about your medical history at the beginning of the study. This information will be used to confirm that you have the relevant medial history to take part in the survey. This information will not enable you to be identifiable from the data and will be held anonymously.

All anonymised data will be used in research publications and will be archived online in line with open science practices. Our legal basis for processing your data is that you have consented to it. The data controller is the University of Essex; the University's Data Protection Officer can be contacted on dpo@essex.ac.uk. Alternatively, you can contact our Research Integrity Manager (please see contact details on the next page).

Participant Information Sheet (version 3)
ERAMS reference: ETH2223-0389
Date: 20/09/2023
Page 1 of 2

Risks and Benefits: This research adheres to the University of Essex ethical guidelines and has been approved by the University of Essex Faculty of Science and Health Ethics Subcommittee. There are no anticipated risks to you taking part, neither is there any direct benefit to your physical or mental health, however, your participation will help with our ongoing research.

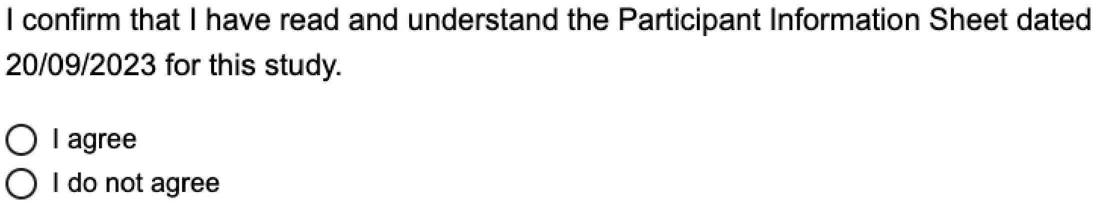
Compensation: At the end of the survey you have the opportunity to receive a £10 amazon e-voucher.

Complaints: If you have any concerns or complaints about any aspect of the study, in the first instance please contact the principal investigator of the project, Dr Katie Daughters (k.daughters@essex.ac.uk). If are still concerned, please contact the departmental Director of Research, Prof Sheina Orbell (sorbell@essex.ac.uk). If you are still not satisfied, please contact the University's Research Integrity Manager (see below).

University of Essex Research Integrity Manager
Mantalena Sotiriadou, Research & Enterprise Office, University of Essex, Wivenhoe Park, CO4 3SQ, Colchester.
Email: ms21994@essex.ac.uk. Phone: 01206-873561

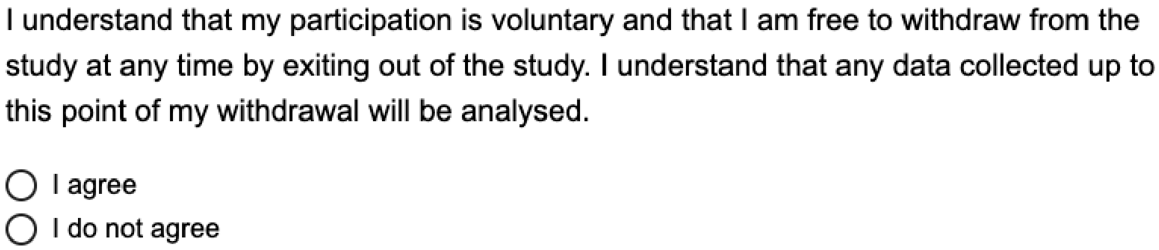
Appendix E

Study One Consent Questions



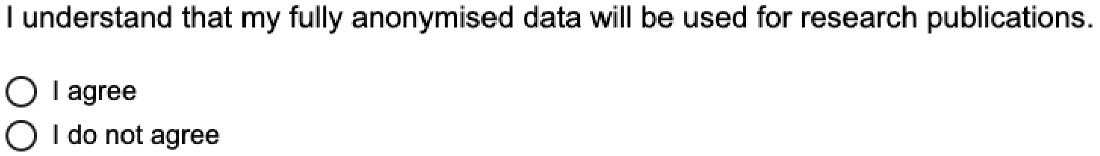
I confirm that I have read and understand the Participant Information Sheet dated 20/09/2023 for this study.

○ I agree
○ I do not agree



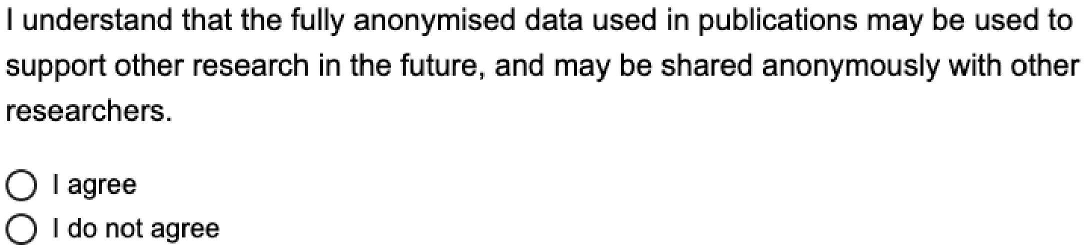
I understand that my participation is voluntary and that I am free to withdraw from the study at any time by exiting out of the study. I understand that any data collected up to this point of my withdrawal will be analysed.

○ I agree
○ I do not agree



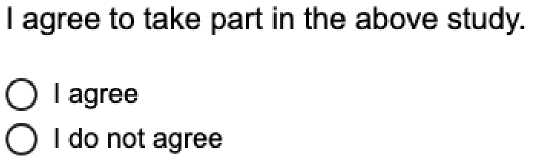
I understand that my fully anonymised data will be used for research publications.

○ I agree
○ I do not agree



I understand that the fully anonymised data used in publications may be used to support other research in the future, and may be shared anonymously with other researchers.

○ I agree
○ I do not agree

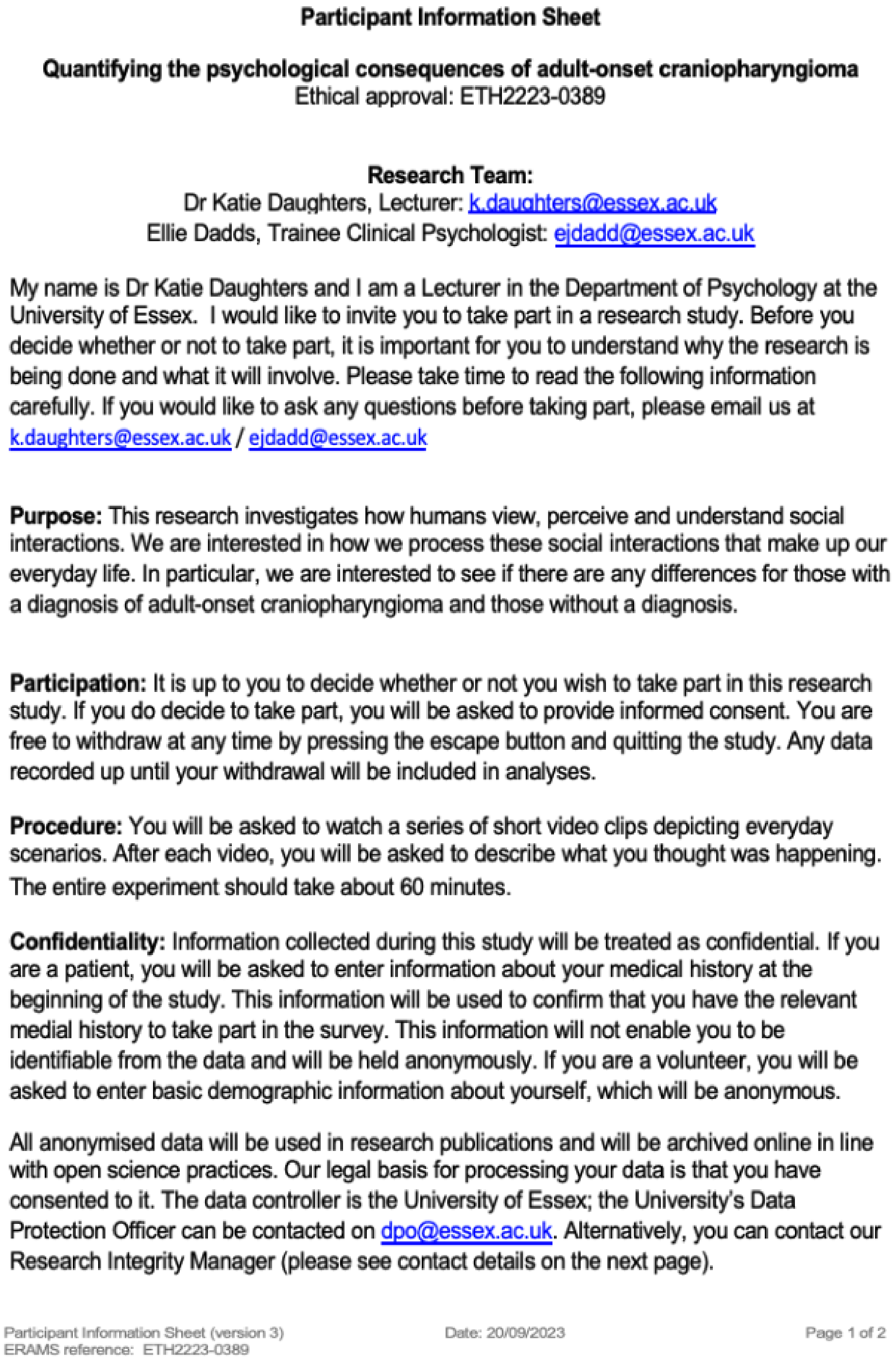


I agree to take part in the above study.

○ I agree
○ I do not agree

Appendix F

Study Two Participant Information Sheet for Patients with AOC



Participant Information Sheet

Quantifying the psychological consequences of adult-onset craniopharyngioma
Ethical approval: ETH2223-0389

Research Team:
Dr Katie Daughters, Lecturer: k.daughters@essex.ac.uk
Ellie Dadds, Trainee Clinical Psychologist: ejdadd@essex.ac.uk

My name is Dr Katie Daughters and I am a Lecturer in the Department of Psychology at the University of Essex. I would like to invite you to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. If you would like to ask any questions before taking part, please email us at k.daughters@essex.ac.uk / ejdadd@essex.ac.uk

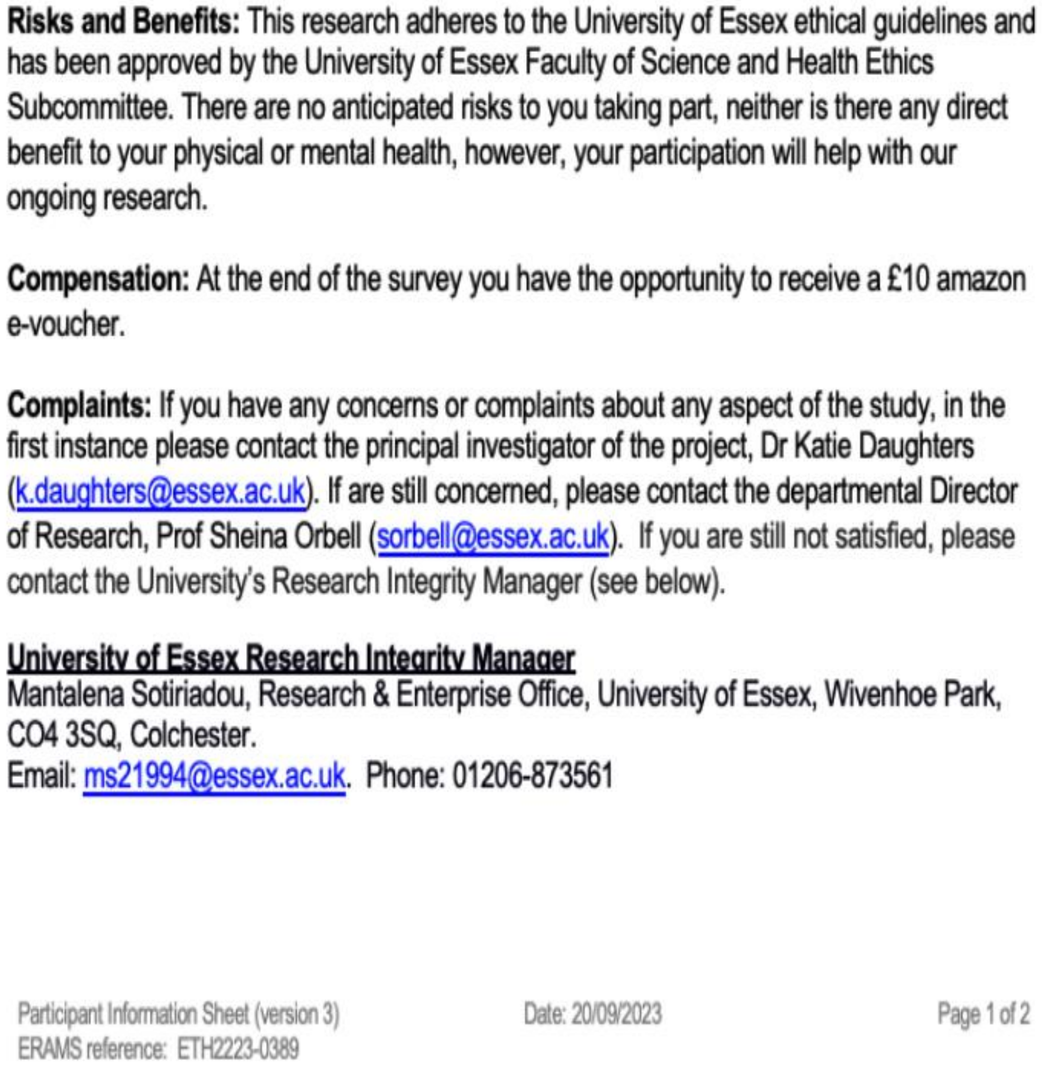
Purpose: This research investigates how humans view, perceive and understand social interactions. We are interested in how we process these social interactions that make up our everyday life. In particular, we are interested to see if there are any differences for those with a diagnosis of adult-onset craniopharyngioma and those without a diagnosis.

Participation: It is up to you to decide whether or not you wish to take part in this research study. If you do decide to take part, you will be asked to provide informed consent. You are free to withdraw at any time by pressing the escape button and quitting the study. Any data recorded up until your withdrawal will be included in analyses.

Procedure: You will be asked to watch a series of short video clips depicting everyday scenarios. After each video, you will be asked to describe what you thought was happening. The entire experiment should take about 60 minutes.

Confidentiality: Information collected during this study will be treated as confidential. If you are a patient, you will be asked to enter information about your medical history at the beginning of the study. This information will be used to confirm that you have the relevant medial history to take part in the survey. This information will not enable you to be identifiable from the data and will be held anonymously. If you are a volunteer, you will be asked to enter basic demographic information about yourself, which will be anonymous.

All anonymised data will be used in research publications and will be archived online in line with open science practices. Our legal basis for processing your data is that you have consented to it. The data controller is the University of Essex; the University's Data Protection Officer can be contacted on dpo@essex.ac.uk. Alternatively, you can contact our Research Integrity Manager (please see contact details on the next page).



Risks and Benefits: This research adheres to the University of Essex ethical guidelines and has been approved by the University of Essex Faculty of Science and Health Ethics Subcommittee. There are no anticipated risks to you taking part, neither is there any direct benefit to your physical or mental health, however, your participation will help with our ongoing research.

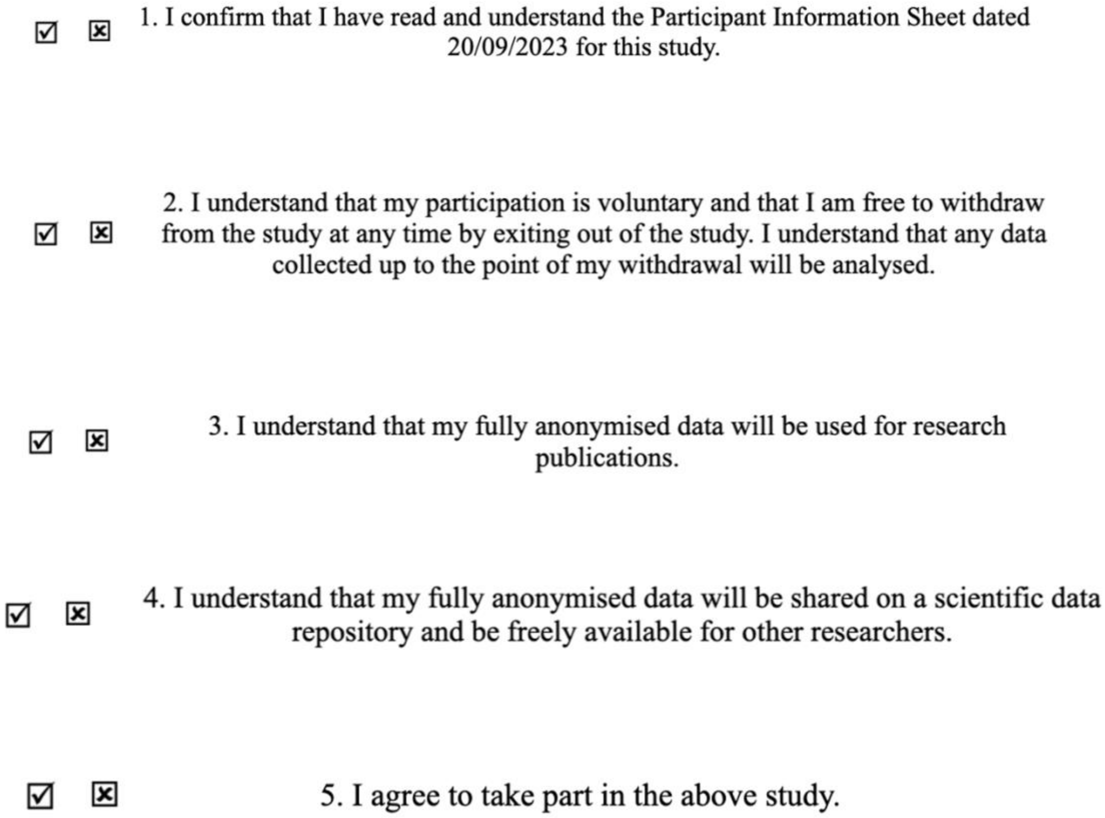
Compensation: At the end of the survey you have the opportunity to receive a £10 amazon e-voucher.

Complaints: If you have any concerns or complaints about any aspect of the study, in the first instance please contact the principal investigator of the project, Dr Katie Daughters (k.daughters@essex.ac.uk). If are still concerned, please contact the departmental Director of Research, Prof Sheina Orbell (sorbell@essex.ac.uk). If you are still not satisfied, please contact the University's Research Integrity Manager (see below).

University of Essex Research Integrity Manager
Mantalena Sotiriadou, Research & Enterprise Office, University of Essex, Wivenhoe Park,
CO4 3SQ, Colchester.
Email: ms21994@essex.ac.uk. Phone: 01206-873561

Appendix G

Study Two Consent Questions



☑ ☒ 1. I confirm that I have read and understand the Participant Information Sheet dated 20/09/2023 for this study.

☑ ☒ 2. I understand that my participation is voluntary and that I am free to withdraw from the study at any time by exiting out of the study. I understand that any data collected up to the point of my withdrawal will be analysed.

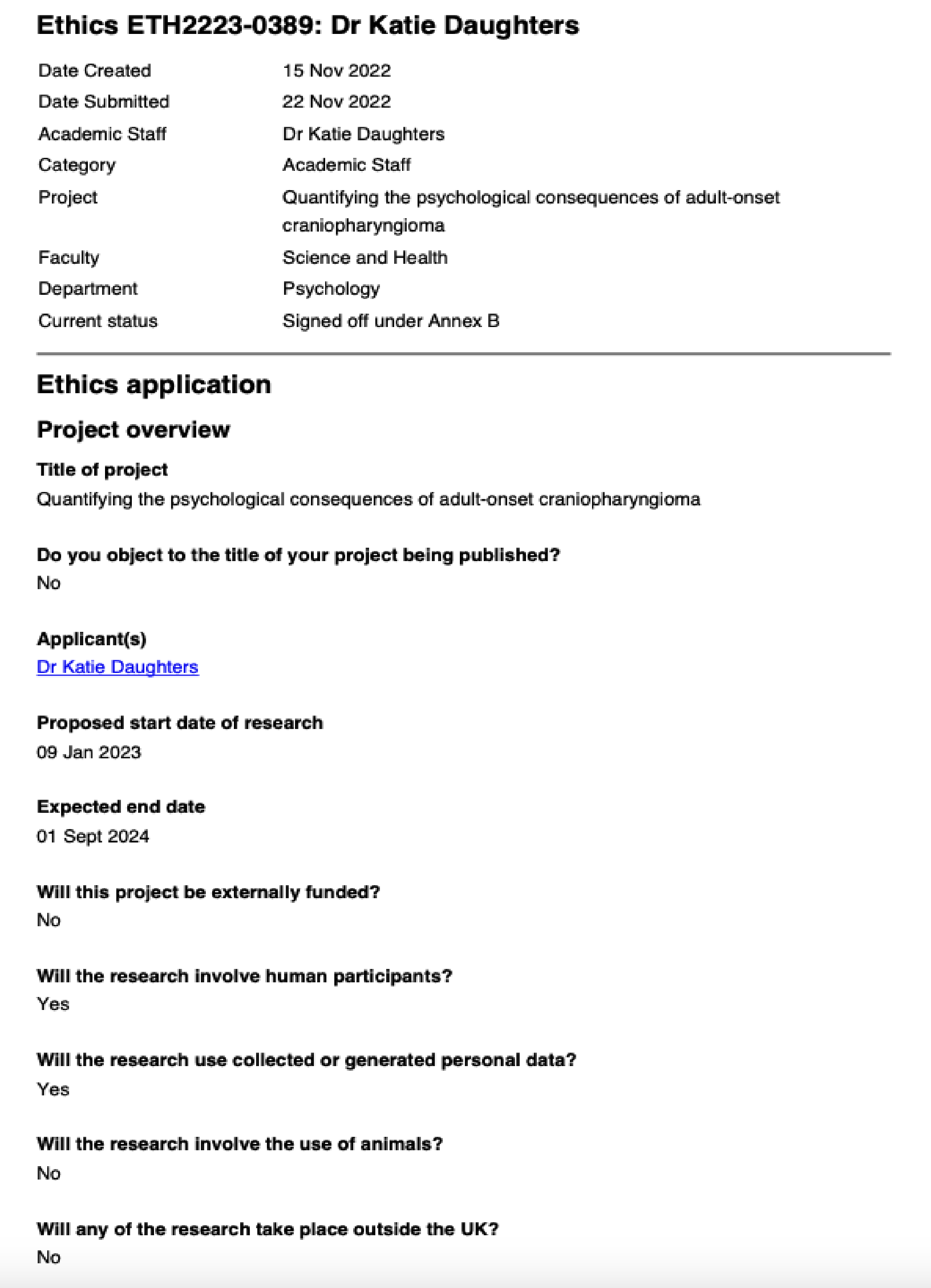
☑ ☒ 3. I understand that my fully anonymised data will be used for research publications.

☑ ☒ 4. I understand that my fully anonymised data will be shared on a scientific data repository and be freely available for other researchers.

☑ ☒ 5. I agree to take part in the above study.

Appendix H

University of Essex Ethics Application and Approval



Ethics ETH2223-0389: Dr Katie Daughters

Date Created	15 Nov 2022
Date Submitted	22 Nov 2022
Academic Staff	Dr Katie Daughters
Category	Academic Staff
Project	Quantifying the psychological consequences of adult-onset craniopharyngioma
Faculty	Science and Health
Department	Psychology
Current status	Signed off under Annex B

Ethics application

Project overview

Title of project
Quantifying the psychological consequences of adult-onset craniopharyngioma

Do you object to the title of your project being published?
No

Applicant(s)
Dr Katie Daughters

Proposed start date of research
09 Jan 2023

Expected end date
01 Sept 2024

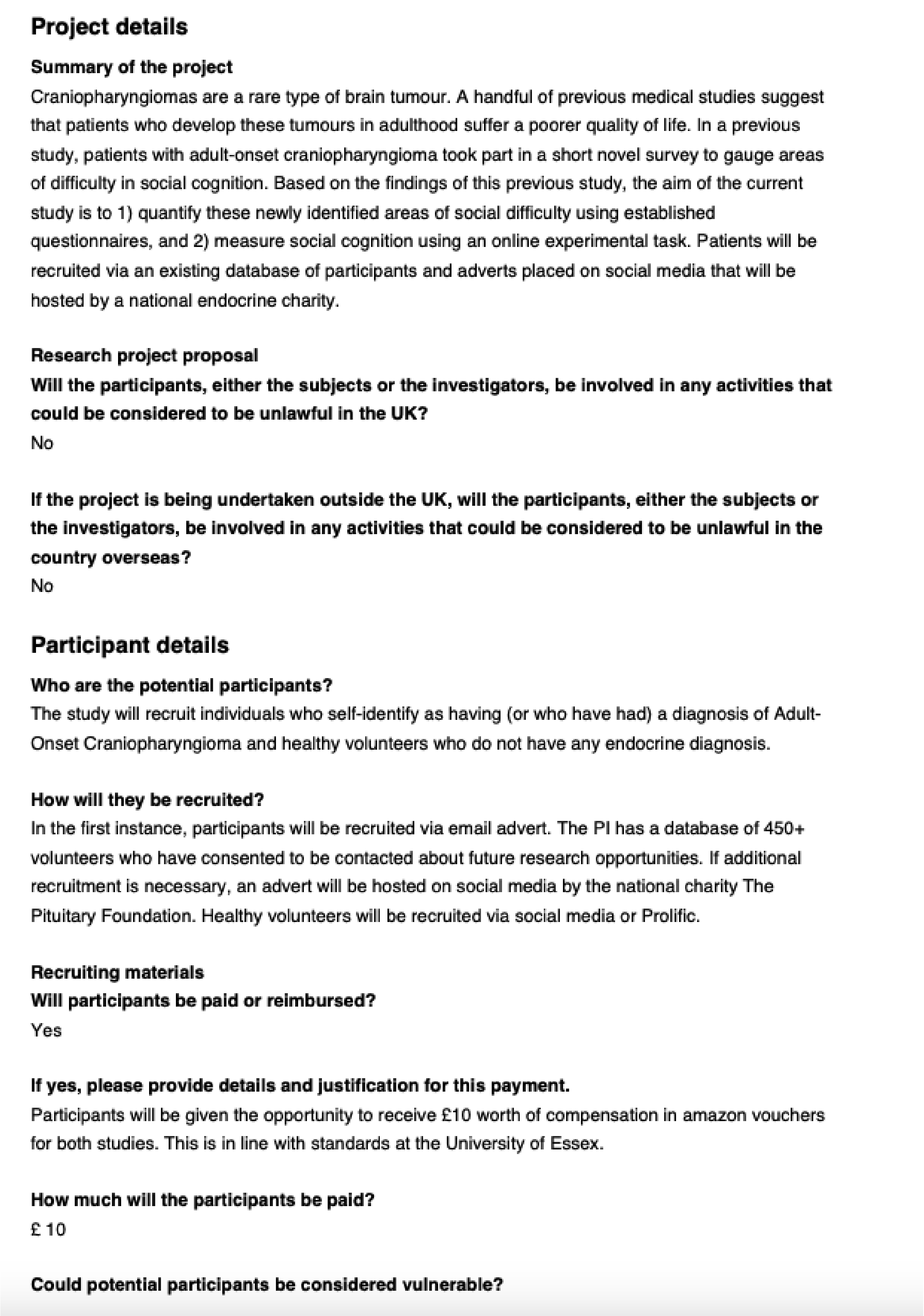
Will this project be externally funded?
No

Will the research involve human participants?
Yes

Will the research use collected or generated personal data?
Yes

Will the research involve the use of animals?
No

Will any of the research take place outside the UK?
No



Project details

Summary of the project

Craniopharyngiomas are a rare type of brain tumour. A handful of previous medical studies suggest that patients who develop these tumours in adulthood suffer a poorer quality of life. In a previous study, patients with adult-onset craniopharyngioma took part in a short novel survey to gauge areas of difficulty in social cognition. Based on the findings of this previous study, the aim of the current study is to 1) quantify these newly identified areas of social difficulty using established questionnaires, and 2) measure social cognition using an online experimental task. Patients will be recruited via an existing database of participants and adverts placed on social media that will be hosted by a national endocrine charity.

Research project proposal

Will the participants, either the subjects or the investigators, be involved in any activities that could be considered to be unlawful in the UK?

No

If the project is being undertaken outside the UK, will the participants, either the subjects or the investigators, be involved in any activities that could be considered to be unlawful in the country overseas?

No

Participant details

Who are the potential participants?

The study will recruit individuals who self-identify as having (or who have had) a diagnosis of Adult-Onset Craniopharyngioma and healthy volunteers who do not have any endocrine diagnosis.

How will they be recruited?

In the first instance, participants will be recruited via email advert. The PI has a database of 450+ volunteers who have consented to be contacted about future research opportunities. If additional recruitment is necessary, an advert will be hosted on social media by the national charity The Pituitary Foundation. Healthy volunteers will be recruited via social media or Prolific.

Recruiting materials

Will participants be paid or reimbursed?

Yes

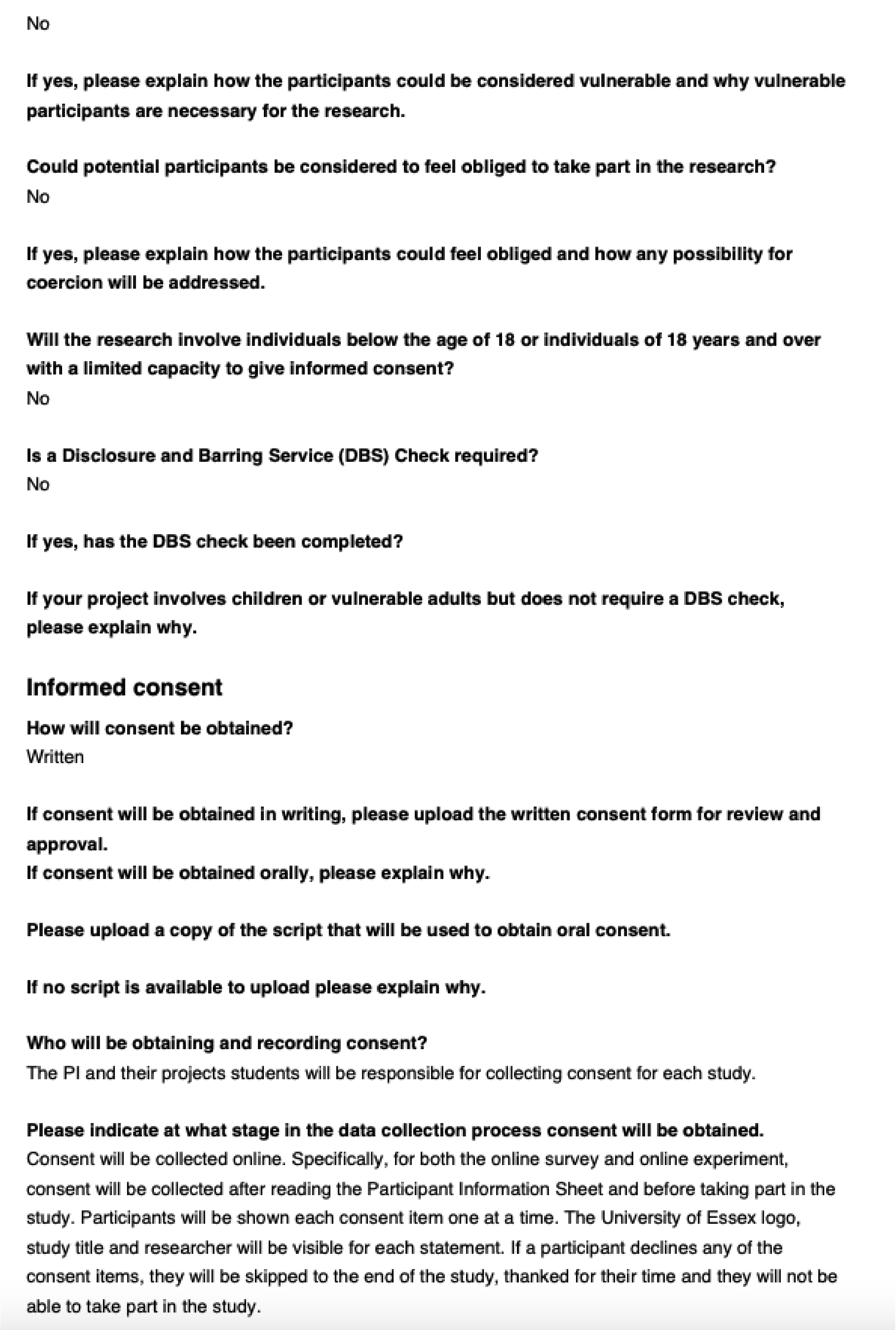
If yes, please provide details and justification for this payment.

Participants will be given the opportunity to receive £10 worth of compensation in amazon vouchers for both studies. This is in line with standards at the University of Essex.

How much will the participants be paid?

£ 10

Could potential participants be considered vulnerable?



No

If yes, please explain how the participants could be considered vulnerable and why vulnerable participants are necessary for the research.

Could potential participants be considered to feel obliged to take part in the research?
No

If yes, please explain how the participants could feel obliged and how any possibility for coercion will be addressed.

Will the research involve individuals below the age of 18 or individuals of 18 years and over with a limited capacity to give informed consent?
No

Is a Disclosure and Barring Service (DBS) Check required?
No

If yes, has the DBS check been completed?

If your project involves children or vulnerable adults but does not require a DBS check, please explain why.

Informed consent

How will consent be obtained?
Written

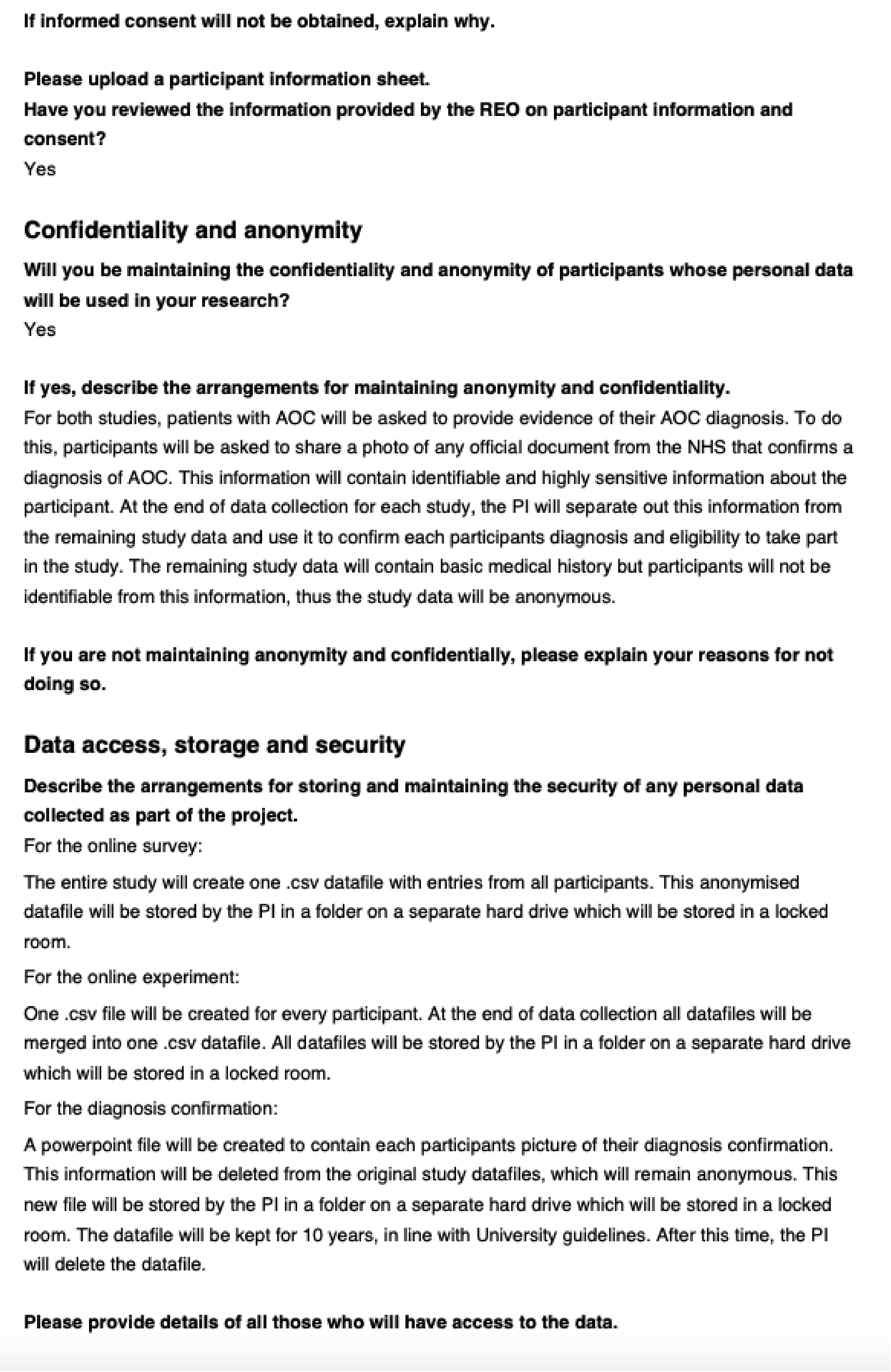
If consent will be obtained in writing, please upload the written consent form for review and approval.
If consent will be obtained orally, please explain why.

Please upload a copy of the script that will be used to obtain oral consent.

If no script is available to upload please explain why.

Who will be obtaining and recording consent?
The PI and their projects students will be responsible for collecting consent for each study.

Please indicate at what stage in the data collection process consent will be obtained.
Consent will be collected online. Specifically, for both the online survey and online experiment, consent will be collected after reading the Participant Information Sheet and before taking part in the study. Participants will be shown each consent item one at a time. The University of Essex logo, study title and researcher will be visible for each statement. If a participant declines any of the consent items, they will be skipped to the end of the study, thanked for their time and they will not be able to take part in the study.



If informed consent will not be obtained, explain why.

Please upload a participant information sheet.

Have you reviewed the information provided by the REO on participant information and consent?

Yes

Confidentiality and anonymity

Will you be maintaining the confidentiality and anonymity of participants whose personal data will be used in your research?

Yes

If yes, describe the arrangements for maintaining anonymity and confidentiality.

For both studies, patients with AOC will be asked to provide evidence of their AOC diagnosis. To do this, participants will be asked to share a photo of any official document from the NHS that confirms a diagnosis of AOC. This information will contain identifiable and highly sensitive information about the participant. At the end of data collection for each study, the PI will separate out this information from the remaining study data and use it to confirm each participants diagnosis and eligibility to take part in the study. The remaining study data will contain basic medical history but participants will not be identifiable from this information, thus the study data will be anonymous.

If you are not maintaining anonymity and confidentially, please explain your reasons for not doing so.

Data access, storage and security

Describe the arrangements for storing and maintaining the security of any personal data collected as part of the project.

For the online survey:

The entire study will create one .csv datafile with entries from all participants. This anonymised datafile will be stored by the PI in a folder on a separate hard drive which will be stored in a locked room.

For the online experiment:

One .csv file will be created for every participant. At the end of data collection all datafiles will be merged into one .csv datafile. All datafiles will be stored by the PI in a folder on a separate hard drive which will be stored in a locked room.

For the diagnosis confirmation:

A powerpoint file will be created to contain each participants picture of their diagnosis confirmation. This information will be deleted from the original study datafiles, which will remain anonymous. This new file will be stored by the PI in a folder on a separate hard drive which will be stored in a locked room. The datafile will be kept for 10 years, in line with University guidelines. After this time, the PI will delete the datafile.

Please provide details of all those who will have access to the data.

The research team (the PI and project students) will have access to the anonymous study datafiles. Cleaned datafiles for each study will also be shared via the OSF in line with open science practices.

Only the PI will have access to the powerpoint file with the non-anonymous data. This file will be securely stored and not accessible to anyone else.

Data sharing

Do you intend to share or archive data generated from this project once it is complete?
Yes

If yes, please describe briefly.
The cleaned anonymous datafile and analysis scripts for each study will be archived on the OSF in line with open science practices.

Please indicate the means by which you intend to share/archive your data:
Openly available from a data repository (e.g. UK Data Archive, University of Essex Research Data Repository, other repository)

If you chose other, please provide more details.

If you do not intend to share data please provide specific reasons why the data will not be made available.

Risk and risk management

Risk Assessment documents

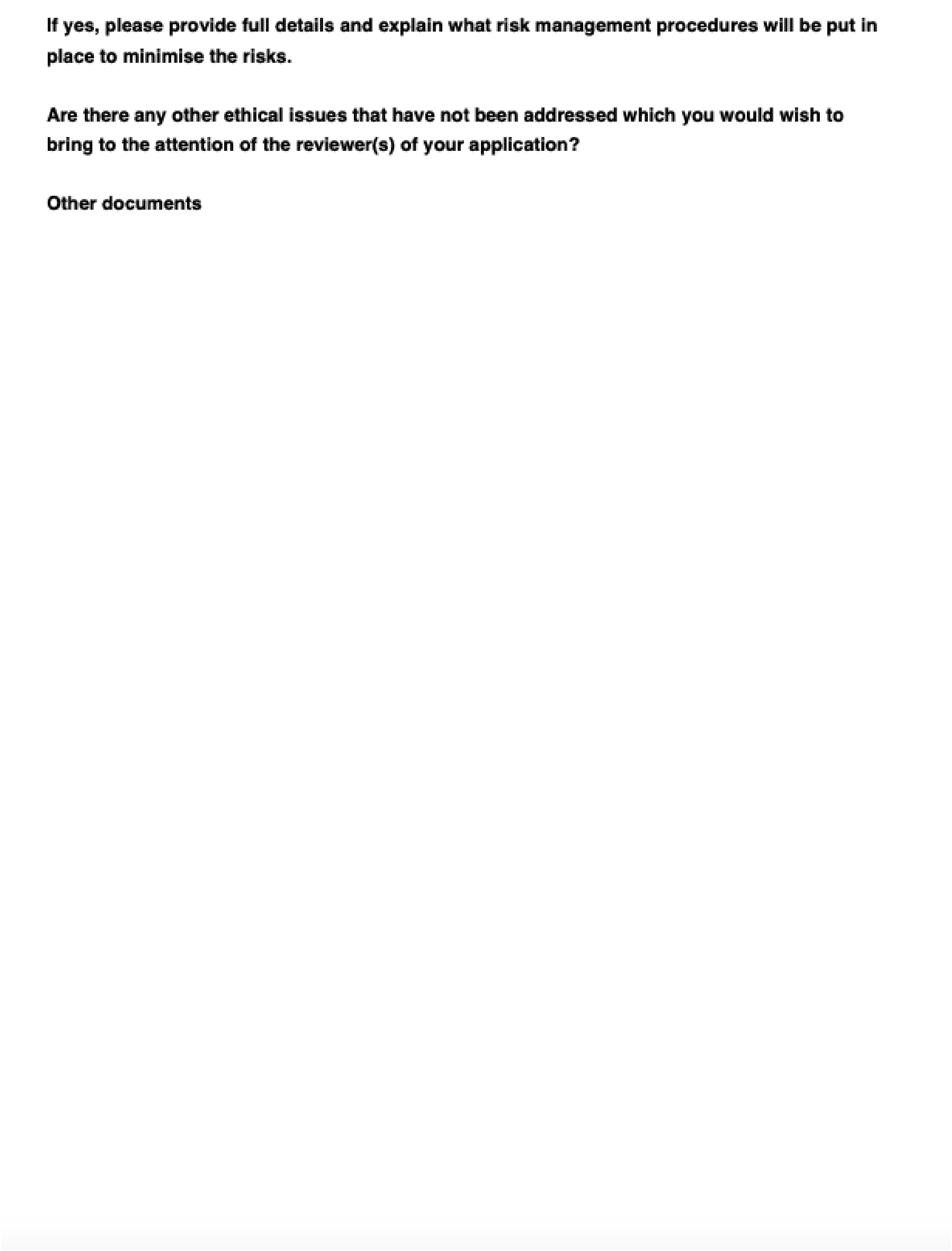
Are there any potential risks (e.g. physical, psychological, social, legal or economic) to participants or subjects associated with the proposed research?
No

If yes, please provide full details and explain what risk management procedures will be put in place to minimise the risks.

Are there any potential risks (e.g. physical, psychological, social, legal or economic) to the researchers working on the proposed research?
No

If yes, please provide full details and explain what risk management procedures will be put in place to minimise the risks.

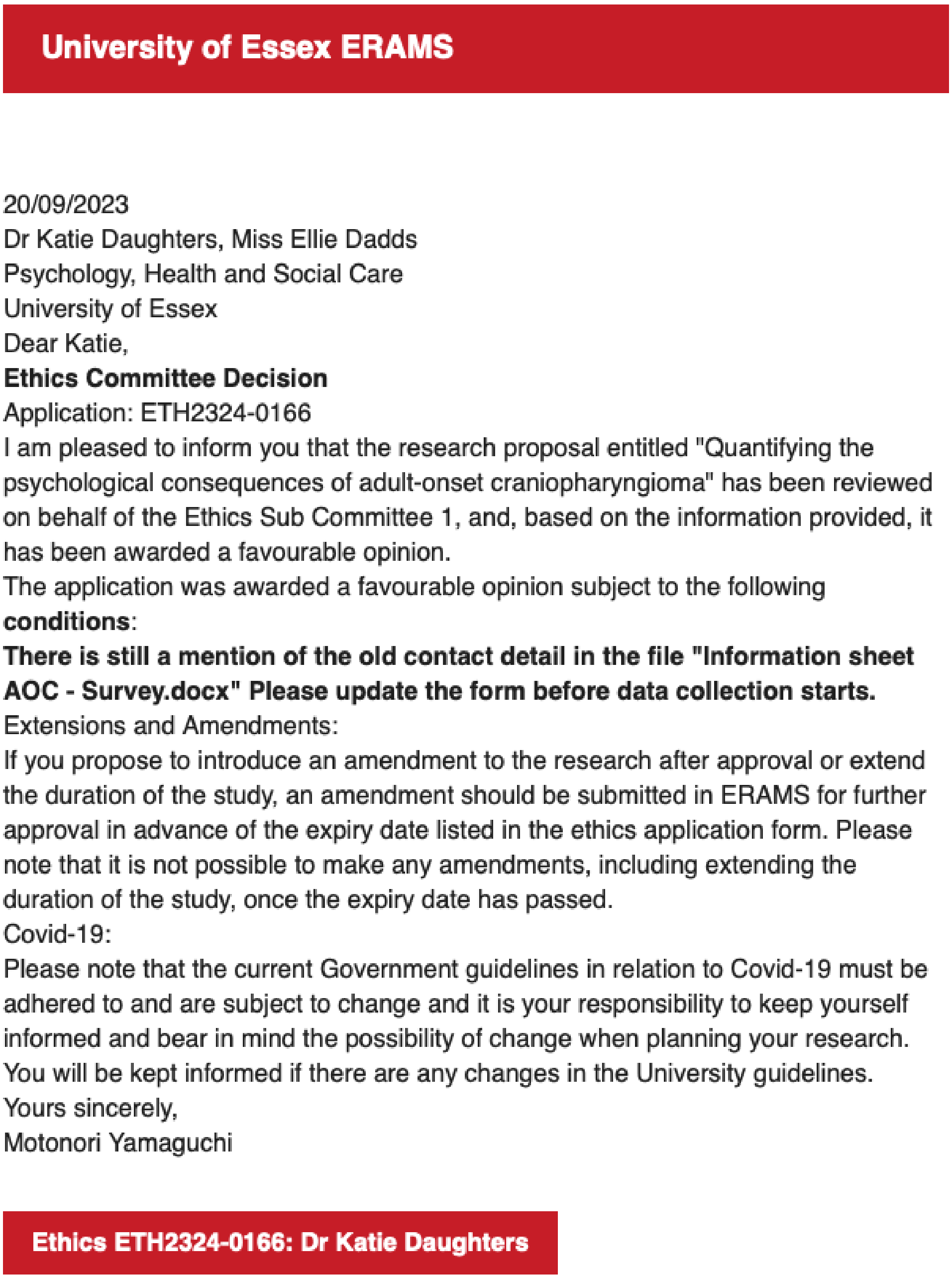
Are there any potential reputational risks to the University as a consequence of undertaking the proposed research?
No



If yes, please provide full details and explain what risk management procedures will be put in place to minimise the risks.

Are there any other ethical issues that have not been addressed which you would wish to bring to the attention of the reviewer(s) of your application?

Other documents



University of Essex ERAMS

20/09/2023
Dr Katie Daughters, Miss Ellie Dadds
Psychology, Health and Social Care
University of Essex

Dear Katie,

Ethics Committee Decision

Application: ETH2324-0166

I am pleased to inform you that the research proposal entitled "Quantifying the psychological consequences of adult-onset craniopharyngioma" has been reviewed on behalf of the Ethics Sub Committee 1, and, based on the information provided, it has been awarded a favourable opinion.

The application was awarded a favourable opinion subject to the following **conditions**:

There is still a mention of the old contact detail in the file "Information sheet AOC - Survey.docx" Please update the form before data collection starts.

Extensions and Amendments:

If you propose to introduce an amendment to the research after approval or extend the duration of the study, an amendment should be submitted in ERAMS for further approval in advance of the expiry date listed in the ethics application form. Please note that it is not possible to make any amendments, including extending the duration of the study, once the expiry date has passed.

Covid-19:

Please note that the current Government guidelines in relation to Covid-19 must be adhered to and are subject to change and it is your responsibility to keep yourself informed and bear in mind the possibility of change when planning your research. You will be kept informed if there are any changes in the University guidelines.

Yours sincerely,
Motonori Yamaguchi

Ethics ETH2324-0166: Dr Katie Daughters